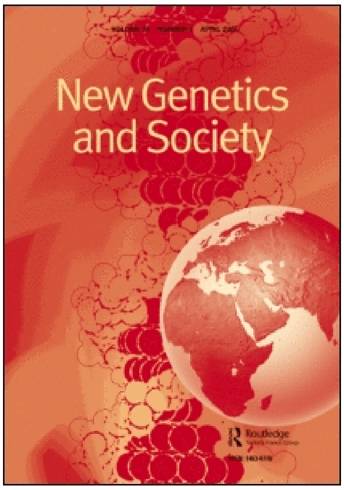

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Stefán Hjörleifsson [a]; Vilhjálmur árnason [b]; Edvin Schei [a]
[a] Section for General Practice, Department of Public Health and Primary Health Care, University of Bergen, Norway [b] Department of Philosophy, University of Iceland, Reykjavik, Iceland

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Decoding the genetics debate: hype and hope in Icelandic news media in 2000 and 2004

Stefán Hjörleifsson,[a]* Vilhjálmur Árnason[b] and Edvin Schei[a]

[a]*Section for General Practice, Department of Public Health and Primary Health Care, University of Bergen, Norway;* [b]*Department of Philosophy, University of Iceland, Reykjavik, Iceland*

The attraction of human genetics is rooted in optimistic projections of possible futures, where present-day problems are to be solved by technologies-to-come. But hyperbolic optimism with its consequent cycles of expectations, investment and disappointment is a threat to users, investors, and the ethical reputation of the biotechnology field. We report a study of the entire news coverage of genetics in Icelandic mass media in 2000 and 2004. All media promoted optimistic industry-based information largely without critical questions concerning scientific uncertainty, health benefits, or ethical challenges. Criticism and deliberation were thematically narrowed down, in 2000 to the issue of "presumed consent" for nationwide participation in a database proposed by the company Decode genetics, and in 2004 to topics concerning Decode's finances. In a discourse of monetary gain and loss, sustained exploration of scientific, moral and cultural issues has little appeal.

Keywords: decode genetics; news media; technology optimism

Introduction

The attraction of human genetics is largely rooted in optimistic projections of possible futures, where present-day problems are to be solved by technologies-to-come. Mass media are central to the production and propagation of scenarios that convey such optimism. Because of the uncertain and promissory nature of practices oriented towards the future, a certain amount of technology hype seems inevitable. Yet unrestrained optimism with its consequent cycles of expectations, investments and disappointment is a threat to investors, users and eventually to trust and the ethical reputation of the biotechnology field, and thus to the societal integration and development of science and biotechnology.

Scientific, commercial and political agents have varying, sometimes competing views and agendas. Yet these agents may have a common interest in the propagation of success stories about genetics-to-come, be it in terms of scientific breakthroughs, monetary profit, or health benefits. Each in their own way, these agents mobilize expectations about how

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*Corresponding author. Email: stefan.hjorleifsson@isf.uib.no

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the future will be transformed for the better through technologies derived from today's genetic research. This raises important challenges in a democratic society. Who speaks on behalf of the general public, who brings balanced information, who asks the difficult questions and provokes the necessary debates? Genetics clearly begs for an active role on the part of the public media. Accurate and critical reporting and questioning is a prerequisite for the shared knowledge and public reflection that societies and individuals need in order to deal with the challenges raised by human genetics in an enlightened and responsible way. Admittedly, public expectations about the benefits and downsides of science are not shaped by the media in a simple, linear fashion (Ten Eyck 2005), and may obviously include insights beyond what is conveyed by journalistic accounts (Priest 1993, Irwin and Wynne 1996). Nevertheless, the portrayal of scientific and biomedical issues in the media is part of and influences people's perceptions of reality, and places constraints on public response to science (Priest 1994, Conrad 1997, Nisbet and Lewenstein 2002). The news media form a part of the public discourse shaping our shared determinations of how we should engage with and make use of human genetic technologies (Condit 1999).

The present study is an analysis of the news media coverage of genetics in Iceland in 2000 and 2004. The public prominence of Decode genetics makes Iceland a particularly interesting setting for such an analysis. In a country with a population of merely 300,000, the commercial enterprise Decode genetics with its 400 employees aiming to involve the entire nation in its research has stirred public awareness since the 1990s. Decode has been heavily criticized internationally for its alleged breach of research ethics, but the company also draws positive attention for its endeavors to translate knowledge about the human genome into practical applications in the health field. The questions we seek to answer include: How are the dynamics of biotechnology expectations reflected in Icelandic news media? What issues in human genetics are given prominence, and how are scientific, ethical, commercial and political challenges depicted and framed? What are the dominant voices, and how do these voices contribute to the production of expectations about human genetics in Iceland?

Before presenting our results, we give a theoretical outline of the concept of technology optimism, drawing on the sociology of technological expectations. In so doing, we include a brief rehearsal of recent studies of the media portrayal of genetics in other countries. A short account of Decode genetics' position in the Icelandic as well as the international context is also provided. Together, this constitutes the background against which our empirical data are presented.

Technology optimism and genetics

Optimism is integral to human situatedness in time. Whereas the present is the only time genuinely "real" to us, past and future are decisive in human agency – memories of past futures enable us to project future presents, and act on them. Any scientific or biotechnological innovation springs from anticipations of possible future solutions to perceived present problems. In order to better grasp the dynamics of the relationship between science, in particular human genetics, and the wider community, we need to be aware of how the future enters human judgment and influences imagination, perception and motivation.

To gain support and funding for their projects, scientists and entrepreneurs conjure up future benefits that convincingly promise to be worth any foreseeable costs. Health benefits, business revenue, national pride, individual fame, and the pure excitement of discovery may contribute to the dynamics of expectations surrounding a scientific or technological enterprise. And in highly competitive surroundings, the most vociferous among many optimistic voices will be heard most clearly. Optimism and shared expectations translate into networks of obligations and aspirations that unite innovators, investors, consumers, regulators and the public media in what have been called "communities of promise" (Van Lente 1993). In this sense, expectations are far from being secondary epiphenomena, but are fundamental to the dynamic processes whereby science and technology operate in the laboratory and in society at large (Hedgecoe and Martin 2003).

The core features of technology optimism are underestimation and neglect of uncertainty, through which laboratory entities are transformed into objects of widely shared speculative promise (Brown 2003). Such optimism has been notorious in the field of human genetics. Yet genetics is deeply affected by uncertainties, dilemmas and challenges (Holtzman and Marteau 2000, Burke and Zimmern 2004), identifiable by questions such as: How broadly should genetic testing for susceptibility to breast cancer be promoted? What is the proper use of genetic tests for nicotine addiction, alcoholism or obesity? What will be the consequences if genetic testing of fetuses and genetic engineering of our offspring becomes commonplace? To what extent do commercial motives in scientific research coincide with the goals of public health authorities?

The lack of reassuring answers to questions such as these reflects the fundamental complexity of biological systems, the probabilistic nature of medical knowledge, the multiplicity of potential futures in any present, and the vulnerability of human agency and systems of governance. In the present study, we have sought to determine whether and to what extent sources of uncertainty and controversy are highlighted or subdued in the mass media coverage of genetics in Iceland.

Brown (2003) shows that expectations vary between different groups of agents such as policy makers, researchers, consumers, investors and patients as these have uneven access to information, and also widely varying needs, obligations and worldviews. Futures are differently interpreted, and expectations emerge from struggles and contests between voices. With increasing distance in space and time from the material complexity of bench science, most uncertainties tend to become harder to see, agents tend to place less emphasis on the fact that many different futures are possible, and the goal of stabilization and persuasion becomes increasingly important. Being far away from the original contingencies of knowledge production, policy makers and the general public are often left with few contextual resources to judge the veracity or probability of promissory claims.

Research fields differ radically in maturity, reflecting the degree to which various problems have had the time to surface and reshape expectations. Expectations tend to be particularly high in the early phases of any innovation. Recent arrivals to the world of biotechnology often require a strong visionary momentum in order to command collaboration and investment. To obtain such a momentum, uncertainty is under-communicated and potential advantages overexposed. The result is hype. Writes Brown (2003): "[H]ype tends to entirely overestimate the near or medium term potential of a field whilst completely misunderstanding longer term value altogether."

In some cases therefore, hype is bound to result in disillusionment and loss of trust in the scientific–industrial–political complex. Yet optimism tends to re-emerge in closely related fields, as agents reorganize in new networks. Thus, the failure of xenotransplantation to revolutionize medicine and the lack of success in gene therapy has certainly not prevented recent optimism about stem cell research and pharmacogenetics. In Iceland, many individuals have suffered considerable financial loss from investing heavily in Decode, yet 90% of the population still volunteer blood samples for research when asked. How can we explain the resilience of optimism in a field like biotechnology, in the face of so many disappointments over a short time span? A possible explanation lies in the long-term collective memories of past futures. History teaches us that present-day technological wonders were developed over many years of stumbling into false theories, blind alleys and costly failures. Yet over time science has produced results that have radically changed the world, suggesting that temporary setbacks may merely be the necessary price to pay in a kind of enterprise that deals with the unforeseeable.

A particularly relevant example of scientists' constant endeavors to sustain optimism is the press release (Brown 2003, Brown and Michael 2003). In their scientific publications, scientists routinely convey uncertainty and awareness of different possible futures. Yet in press releases, the same researchers as a rule project one single desirable future where present-day problems have been solved by means of the scientific achievement in case. Press releases are held in an optimistic language that directs readers' attention away from uncertainty, notwithstanding the sober uncertainty clauses regularly included.

In contrast to the press release genre, scientists and biotechnology companies, in their formal dealings with the stock exchange, inform investors openly about potential futures that differ dramatically from their optimistic hopes. Financial hype thus coexists with firmly regulated descriptions of less optimistic futures. The self-portrayal of biotechnology and genetic research institutions is pervasively influenced by the requirement to secure funding, and this is achieved by a complex eat-the-cake-and-have-it-too mixture of thrilling technology optimism and ritual uncertainty statements (Rose 2000, Fortun 2001, Fleising 2005).

Recent studies of the news coverage of human genetics in different countries demonstrate a number of consistent features (among others Conrad 1999, 2001, Petersen 2001, Kitzinger *et al.* 2002, Bubela and Caulfield 2004, Tammpuu 2004, Racine *et al.* 2006, Väliverronen 2006): The pursuit of genetic technologies is usually portrayed as highly desirable – they hold great potential for alleviating and preventing suffering, and this will yield financial benefits. Genetic technologies are expected to provide personalized medical services and individual control over health. The role of environmental and social factors in disease is seldom discussed alongside the genetic aspects. Concerns about tampering with nature, discrimination of individuals, and replicating eugenic atrocities of the past are also recurring themes in the media. Typically however, coverage of genetics is of an either/or nature, which means that attempts to discuss how elements from optimistic and pessimistic futures can coexist are rare. The total framing of ethical and social challenges tends to be dominated by scientific and political experts, and scientific disagreement about research findings or the principles on which research is conducted is seldom reported. Journalists infrequently question research findings or predictions about future benefits made by researchers. Suggestive metaphors, expert claims and "human interest" stories converge on the message that if only certain ethical and legal concerns are attended to, genetics will deliver great benefits. The regular occurrence of dystopian themes allows scientists to ensure that their own research is of the right kind and is subject to appropriate regulation, and thus serves to highlight the ethical standards and the beneficial implications of human genetics.

When reporting from scientific publications in the field of genetics, journalists in the public media usually do not question the truthfulness or biases of their sources (Bubela and Caulfield 2004, Väliverronen 2006). The validity of human genetic discoveries and the vested interests of researchers are rarely discussed (Holtzman *et al.* 2005). Beyond the generally optimistic nature of scientific press releases which has already been mentioned, another reason for this seems to be that scientists are by far the most important source of information for journalists, and critical perspectives are usually included in media reports only when available from scholars ready to stand forward with such criticism (Conrad 1999).

Commercial pressure may also encourage the news media to avoid discussion of uncertainty and ethical challenges when reporting about genetics and health issues. A recent Canadian study indicates that such factors may be at work when press agencies produce "expedient and consumable" images of genetics, generating and supporting expectations that investment in genetics will deliver economic benefits without major ethical dilemmas (Racine *et al.* 2006). And if the prevailing liberal economic ideology provides a particularly fertile environment for the development of human genetic technologies (Birch 2006), one way in which this may become evident is through an amalgamation of genetics and economy in media reports. Interest in economic profit is plentiful in the news media, and media companies that are required to frame their news reports so as to increase sales and produce revenue, are likely to embrace stories where optimism about health benefits and economic profit prevail. Thus, although investing in optimistic futures from an angle that is different from that of scientists, industrialists and public authorities, the news media may have their own motives for sustaining bright expectations about technology, health and finances.

Why is inflated technology optimism a problem? Frequent disillusionment caused by hype can have adverse long-term consequences for scientific development and the integration of biotechnology in society. Investors and funding agencies may pull out of fields with a reputation of unfulfilled promises. Disillusionment can erode consumers', citizens' and politicians' trust in research and technology. Thus, hype can indirectly be the cause of hostile reactions towards biotechnology and misdirected regulatory efforts. Another cost of exaggerations is that high-quality scientific projects presented in less inflated prose may succumb in the competition for funding. Technology optimism may even go hand in hand with a corresponding neglect of social and political determinants of suffering, with the result that inappropriate emphasis is placed on technological fixes for challenges that cannot be properly resolved through technical means (Árnason and Hjörleifsson 2007).

As previously stated, hype involves oversimplification, and this applies also to the field of bioethics. Árnason (2004) has argued that legal and technical debate in Iceland about issues of privacy of database information largely eclipsed other moral and political issues. In other countries it has been argued that the debate about genetic research has been dominated by the issue of "informed consent", while other relevant topics tend to be ignored (e.g. Hoeyer and Tutton 2005). According to Evans' (2002) study of scholarly and policy debates about human genetic technologies in the US, religious and political stakeholders criticizing the ends for which genetic technologies promise to provide the means have gradually disappeared from these debates. Moral debate has been replaced by a bureaucratically framed discourse concerned with technical risks and the means for achieving certain ends, assumed to be beneficial. This "thinning" of debate over human genetic technologies excludes concerns that may be present among the public but not easily framed in terms of risk.

Genetics in Iceland

The "Decode experience" is one of the "past futures" that has made researchers and policy makers in different countries aware of the dangers of ignoring public debate and public expectations about genetics (Rose 2001). Decode genetics came under fire in the late 1990s because of its plans for establishing a population-based research database complex in Iceland (Pálsson and Harðardóttir 2002, Árnason 2004). The so-called Health Sector Database (HSD), which provoked the controversy, would comprise healthcare information from every Icelander who had not explicitly opted out of the HSD. The government supported Decode's plans, and a legal environment was created to make the HSD possible. The plans were criticized and opposed on grounds of research ethics principles and arguments to the effect that commercial interests might run counter to the interests of the Icelandic population. The HSD has not been established to this day, and it seems likely that if Decode and Icelandic authorities had based participation on explicit consent from individuals, this would have increased the chances of establishing the HSD.

In spite of the company's defeat in the HSD case, Decode has obtained blood samples and limited phenotype information from more than 100,000 individuals. Thus, more than 50% of the adult population in Iceland has contributed to the company's research, and according to the company itself more than 90% of the public agree when asked to contribute to Decode's research (K. Kristjánsson, personal communication, 12 May 2004). Decode is increasingly emphasizing downstream research based on its numerous genetic discoveries. Pharmaceutical compounds intended for preventive treatment against heart attack and peripheral artery disease are being developed and tested in clinical trials in Iceland as well as in the United States. The company has launched predictive DNA-based tests in diabetes type II, atrial fibrillation and early-onset heart attack, and tests for breast cancer, prostate cancer and glaucoma are said to be under development.

Icelandic society is small enough for issues in the public domain to easily reach national significance. The public is educated and literate; and several newspapers, radio and television stations provide national news services. Some social scientists as well as representatives of Decode have suggested that the Icelandic HSD debate was a noteworthy example of successful democratic deliberation and decision-making in the case of human genetics (Pálsson and Rabinow 1999, Gulcher and Stefánsson 2000). Others have analyzed the parliament debate leading up to the HSD act and argued that although extensive and conspicuous to the public, this debate fell short of procedural and substantive criteria of democratic decision-making (Árnason and Árnason 2004). A study of the most influential Icelandic newspaper between 1998 and 2000 provides a catalogue of the discussants and thoroughly traces the arguments employed and their socio-historical genealogy. One of the conclusions of this study is that Icelandic cultural debate in this case provided "minimal space for a true dialogue" (Pálsson and Harðardóttir 2002). In another study of the media coverage of Decode up to 2002, Árnason and Simpson (2003) conclude that despite the vocal opposition to the HSD, Decode succeeded in situating the debate about genetics within a frame of historic pride and national identity, striking chords of literature and literacy, popular genealogy, entrepreneurship and achievement in the hearts of the Icelandic people.

Material and methods

All items discussing genetics (human or non-human) in major Icelandic news media in 2000 and 2004, as well as press releases from Decode in the same period were included. The 1531 media items were obtained as photocopies of articles from five newspapers (*Morgunblaðið*, *Fréttablaðið*, *DV*, *Viðskiptablaðið* and *Dagur*) and verbatim transcripts from three TV stations (*Stöð 2*, *Skjár 1* and public broadcast *RÚV*) and two radio stations (*Bylgjan* and public broadcast *RÚV*) from a media monitoring service. Following a primary reading of all items for orientation, a coding framework with categories for (1) thematic focus and (2) evaluative framing was developed through an iterative process. Starting from the researchers' initial perceptions of thematic distinctions, the categories were developed through repeated coding of 40 randomly chosen items. The categories were further specified and consistency was improved by independent coding by two of the researchers of another 40 randomly chosen items.[1] All media items were then categorized by a single researcher, each item being assigned to more than one thematic focus category when appropriate (e.g. a single item might focus on business as well as scientific issues), and each category being independently qualified by assigning it to one of the evaluative framing categories (e.g. while in a given item scientific issues might be framed in a positive manner, the same item might be coded as framing business issues in a neutral manner). Finally, strategically selected items were analyzed for the framing of benefits and challenges raised by genetics, and the relationship between genetics, the general public and regulatory requirements.

Results

The quantitative results of the coding are shown in Table 1. In the text below, the results are ordered by categories derived from the qualitative analysis. All text in double quotes is the authors' translation into English from relevant media items.[2]

Optimism and pride derived from press releases and staged events

Each press release and event staged by Decode generated a series of media items. Quotations from press releases frequently formed the narrative basis of shorter items, while the framing of longer items was also determined by interviews with Decode spokespersons, most commonly the company's chief executive officer and founder. In most items, the views presented by Decode were not questioned or critically commented upon.

An example demonstrating the influence of Decode is the press release and press conference on 19 October 2004, occasioned by the completion of a clinical trial of a drug for preventing heart attack. Over three days these events produced three radio items, three TV items and five newspaper items. Ten of these items reproduced the information provided by Decode, highlighting expectations that great benefits would soon be achieved, under headings such as "New heart drug around the corner" (Fréttablaðið 2004a), or "The first drug which is developed on the basis of a disease gene" (Morgunblaðið 2004b). One item was a positive commentary on the way these results were influencing the value of the company's shares (Fréttablaðið 2004b). Five out of six broadcast items were based on interviews with Decode spokespersons, with the sixth quoting a cardiovascular specialist saying that "this is great news about a new heart drug … it is

Table 1. Framing of genetics in Icelandic news media

	Total		Business		Science		Health		Other	
	N	%	N	%	N	%	N	%	N	%
2000: 1271 items covering 1744 issues										
Positive	861	49.4	285	44.2	327	45.3	154	82.8	95	49.7
Neutral/balanced	697	40.0	290	45.0	293	40.6	28	15.1	86	45.0
Negative	186	10.7	70	10.9	102	14.1	4	2.2	10	5.2
Total	1744	100.0	645	100.0	722	100.0	186	100.0	191	100.0
% of total	100.0		50.7		56.8		14.6		15.0	
2004: 397 items covering 566 issues										
Positive	298	52.7	107	37.5	100	67.6	59	88.1	32	48.5
Neutral/balanced	235	41.5	150	52.6	44	29.7	8	11.9	33	50.0
Negative	33	5.8	28	9.8	4	2.7	0	0.0	1	1.5
Total	566	100.0	285	100.0	148	100.0	67	100.0	66	100.0
% of total	100.0		71.8		37.3		16.9		16.6	

wonderful that an Icelandic company has such success" (RÚV 2004d 19 October 2004). While some of the items included brief comments about the uncertainty involved, these caveats shared two features: First, they originated from Decode spokespersons, either through press releases, press conferences or interviews, and were not pursued by journalists. Second, they were embedded in an optimistic frame, creating the overall expectation that one could count on further positive results, as in the following quotation from the company's chief executive officer: "[T]he company is now much closer to having a product on the market. Although nothing is certain in this regard. What remains is a comprehensive clinical trial which will be conducted in many countries as the intention is to market the drug globally" (RÚV 2004c 19 October 2004).

We thus found a thoroughly positive media presentation of Decode's research, initiation of new studies and cooperation with international industry or Icelandic and international institutions. Scientific achievement and expectations about healthcare benefit and economic gain were highlighted; processes leading to the events covered were portrayed as outstanding feats, and Decode as a leader in its field, utilizing the most effective methods to search for new knowledge, with competitive advantages of eminent scientists and the unique features of Icelandic heritage and healthcare. A further example is Decode's study of Parkinson's disease:

> We have designed a very interesting epidemiological study, and it has now been published in what I believe is the best journal publishing the results of medical research today. [. . .] [P]eople regard this as very important work. (Morgunblaðið 2000g)

Caveats, although included in some of the interviews, were never reflected in the headlines and did not affect the positive framing. Neither did this category of items include discussion of ethical challenges akin to the dilemmas outlined in the introduction to this paper. When Decode spokespersons and expert commentators touched on scientific uncertainty and complexity in interviews, journalists consistently abstained from follow-up questions. In fact, we found three occurrences only where the coverage resulting from events staged by Decode was accompanied by critical comments. On each of these occasions the criticism was a side issue in the media, with the total framing entirely positive. To illustrate, we report this in some detail.

When a contract between Decode, the regional hospital in the city of Akureyri and the University of Akureyri was signed under broad media coverage, the president of the Icelandic Medical Association and the leader of *Mannvernd*, an association established in Iceland in opposition to the HSD plan, were among the persons interviewed (Dagur 2000c). Both criticized the contract for different reasons, but their points of view were not pursued by journalists and were in effect overshadowed by the general enthusiasm for Decode's research and the "watershed" benefits this contract would carry for the Akureyri community (Morgunblaðið 2000h).

Secondly, when Decode announced that variability in a certain region of the human genome is associated with Alzheimer's disease, one media report featuring an interview with an Icelandic doctor emphasized that this did not guarantee that the treatment of Alzheimer's disease would be improved, and that it would take time to ascertain whether this would be the case or not (RÚV 2000c 18 August 2000). In another item, Decode's chief executive officer touched on the same uncertainty, stating that "[t]here is no certainty or guarantee that these results will ever influence the treatment of this disease". Again however, under the heading "Decode and Roche announce important milestone in Alzheimer research: Makes it possible to develop new methods for diagnosing the disease", the total framing highlighted the expectation that healthcare benefits would follow, the efficiency of Decode in producing these and similar results, and the possibility that Decode might reach agreement with other pharmaceutical companies in addition to Roche (Morgunblaðið 2000b).

Finally, when the publication of Decode's study on the genetics of heart attack in *Nature Genetics* was reported in the *New York Times* (2004), this included critical comments from a number of US scientists about the validity and implications of the study. Icelandic media reported these critical comments (e.g. Dagblaðið 2004), but no further analysis of the issue was attempted and the only response elicited was a comment by Decode's chief executive officer in a TV interview, stating that disputes about research findings are integral to the progress of science: "We are bridging the gap between what is known and what is not known, and if people didn't have different opinions about this, something would be wrong" (RÚV 2004b 2 February 2004).

Business thrills, science and health benefits unquestioned

Business issues were covered in 50.7% of all media items about genetics in 2000, rising to 71.8% in 2004. The value of Decode's shares was the most commonly discussed topic, while the financial situation of Decode in general received broad coverage. Frequently, short news items were neutrally framed, i.e. just reporting matter-of-factly that the shares were falling or rising (e.g. Stöð 2 29 July 2004). In other items, negative or positive framing was applied, sometimes questioning the ability of Decode to survive long-standing financial loss, but more frequently signaling enthusiasm and optimism about success for the company. Some of the clearest examples of this enthusiasm were seen at the time of Decode's registration on the NASDAQ stock exchange in the US. This first registration of an Icelandic company on a foreign stock exchange was covered passionately as demonstrated in the following statement made by an Icelandic market analyst:

> This is a very big day for the Icelandic financial sector and I would say for the entire national economy. … We are talking about tremendous amounts of money. … This will for example help correct our foreign trade balance. … We are now exporting services … intellectual capacity and … Icelandic knowledge, Icelandic information, Icelandic genes. (RÚV 2000b 18 July 2000)

In many items, coverage of business issues was accompanied by positively or neutrally framed science and health issues, implying that Decode's research is sound and will result in healthcare benefits if only the company survives a demanding financial situation, i.e. if only "Decode is able to turn its scientific discoveries into business opportunities" (Viðskiptablaðið 2004). Often, the potential to improve healthcare was stated briefly, as in: "The purpose of the company is to search for genes which cause disease in Iceland

and use that knowledge to improve healthcare", a statement found in an op-ed about the rising value of Decode's shares in Iceland prior to the NASDAQ registration (Morgunblaðið 2000c). In other items, healthcare benefits were even more implicit, in the sense that the only uncertainty discussed was of a financial nature. Thus, in a radio interview commenting on a net loss of €31 million during the first six months of 2004, Decode's chief executive officer stated that the company was now concentrating on drug development, and its drug candidate for heart attack ought to provide great revenue in "the fairly close future", and following the trials for this drug, "probably a drug against asthma, then a drug against peripheral arterial occlusion, and then a drug against stroke, and then a drug against schizophrenia" (RÚV 2004a 29 July 2004).

Thus, the scientific quality and medical benefits of Decode's projects were mostly taken for granted or briefly confirmed in items covering business issues. Again, however, the exceptions are illuminating. Prior to the NASDAQ registration, when Decode's registration document with the US Securities and Exchange Commission (SEC) was filed in 2000, Icelandic media reproduced the list of potential obstacles which might prevent Decode from reaching its goals. Most of the potential problems relate to business circumstances, as in: "If losses are incurred for a longer period of time than predicted, the company may be unable to continue its operations", e.g. due to "fierce competition with other biotechnology companies and research institutions". Scientific uncertainty was also stated explicitly, however: "The company's business plans are based on new research methods whose validity has not been proven" (Morgunblaðið 2000a). But this fundamental uncertainty about the scientific results and medical implications of Decode's studies was absent from the coverage of the registration event itself, and was not incorporated into subsequent coverage of business issues.

Finally, in a small number of items not covering business issues, methodological uncertainty in genetics was discussed. The newspaper *Morgunblaðið* on several occasions brought featured items explaining the science of genetics and its potential for use in healthcare. When an impressive 13 pages were devoted to human and non-human genetics (Morgunblaðið 2000f), methodological uncertainty was discussed briefly in five out of 27 items, including the current lack of success in gene therapy, and uncertainty about the long-term consequences of genetic modification of food and crops. The total framing of scientific and health issues was optimistic or neutral in all items, typically reflected in headlines such as "An example of how easily genetic studies can be done in Iceland". However, apart from one item mentioning that "doctors and others still disagree about the contribution of genes to disease", we found no discussion about the relative roles of genetic and non-genetic causes of disease in our entire material, and neither was there any discussion about the relative merits of genetics and public health or political measures in preventing disease.

The presence and absence of explicitly moral positions

A category of positively and negatively framed op-eds published mainly in 2000 were based on arguments of a distinctively moral nature. Positively framed op-eds were signed by different individuals, sometimes on behalf of patient organizations, emphasizing the duty of Icelandic citizens to participate in research bound to improve health for large groups of people (e.g. Morgunblaðið 2000d). Negatively framed op-eds typically stated that regulation should be stricter, Icelandic authorities were guilty of serving the interests of Decode rather than their citizens, and Decode should be considered a foreign company exploiting Icelandic resources. Many of these items were signed by individuals representing *Mannvernd* (e.g. Morgunblaðið 2000i). *Mannvernd*'s campaign against Decode received a certain media attention, with some news items reporting their criticism of the "opting out" principle as well as insufficient anonymization of data, e.g. under the heading "Patients' rights not protected" (Stöð 2 27 August 2000).

Similarly in 2000, the president of the Icelandic Medical Association (IMA) explained in interviews that IMA would not cooperate with Decode unless the "opting out" principle were abandoned (e.g. Morgunblaðið 2000e). The media brought balanced reports of this issue, explicitly framing the disagreement between Decode and the IMA as a moral one (e.g. Bylgjan 2000). The IMA based its case on research ethics principles, such as the right to withdraw from participation in research and the importance for doctors as guardians of medical records to know of patients' explicit consent.

State church leaders and other religious authorities did not contribute to public debate about genetics in the news media in 2000 or 2004, with the exception of three newspaper items in which a priest and a theologian submitted that research and genetic technologies ought to be regulated in order to secure respect for human dignity. One of these items included criticism of Icelandic state church authorities for being absent from public debate about genetics (Dagblaðið 2000).

A few newspaper items were explicitly concerned with bioethics: Icelandic scholars initiating and participating in research projects, and prominent bioethicists visiting Iceland or commenting on Decode from abroad. In three interviews with international scholars the relationship between science and society was discussed in light of the concept of trust and the consent procedure, and it was pointed out that as science must engage with the unknown, society should debate the social and economic uncertainties involved (Dagur 2000a,b; Morgunblaðið 2004d). None of these topics was subsequently referred to by non-bioethics discussants, and in general we were unable to find indications that bioethics agendas influenced the news coverage and framing of genetics. Again, the single exception to this finding is illuminating. In June 2000, the *New England Journal of Medicine* published a commentary by George Annas (2000), professor in health law at Boston University, criticizing the commercialization of research in Iceland and the plans to enter healthcare information into the HSD without individual consent. When Icelandic media reported Annas' critique (e.g. RÚV 2000a 16 June 2000), Decode's chief executive officer responded by accusing Annas of holding vested interests, because of alleged financial ties with a related research project in the US. The chief executive officer also maintained that much of the criticism leveled against Decode locally and internationally originated from individuals seeking to damage Decode due to their own financial interests (Morgunblaðið 2000j).

In 2000, Decode donated €7.5 million worth of its shares to the establishment of a charity for the welfare of Icelandic children. Many of the items coded as "other" in

Table 2. Benefits that different agents may receive from promoting optimism regarding Decode's research

Decode genetics	Medical community	Patients	General public	Journalists/media	Public authorities
Improving regulatory conditions	Confirming medical authority	Mobilizing hope that relief will be provided	Avoiding conflict or embarrassment		Creating high-tech job opportunities
Recruiting research participants	Staying at the forefront of progress	Legitimizing suffering	Promoting image of nation as entrepren-eurial, dynamic and progressive, and drawing international attention		Boosting national economy
Mobilizing financial support			Securing financial gain		Demonstrating leadership

Table 2 were concerned with grants made to the benefit of disadvantaged children or other public benefit initiatives taken by Decode. These items were framed in a positive or more infrequently neutral manner. In two newspaper articles typical of this coverage, Decode's chief executive officer was quoted saying that the purpose of the charity was "to remove some of the darkness which has been imposed on these children" (Morgunblaðið 2004c), and that in modern capitalist society companies should contribute to common welfare through donations (Morgunblaðið 2004a).

Conclusion

Optimistic visions are integral to innovation. Such visions mobilize and legitimize support for certain attempts to solve perceived problems. However, the price of optimism is a relative neglect of uncertainty, complexity, costs and harm in futures different from the one wished for. Since futures tend not to manifest themselves according to plans and previsions, it is reasonable to prepare for alternative futures. In the case of genetics this needs to be done by developing multiple and competing visions of changes and challenges implied by genetic research and genetic technologies-to-come. The media play a major role in shaping people's perception of reality and hence influence public expectations and deliberation. In tiny Iceland, genetics has gained an unusually prominent position in public awareness. In this cultural climate, basic scientific discoveries, potential health benefits, ethics and money issues related to genetics would be expected to abound and to be reflected upon in the public discourse.

The present study demonstrates that in 2000 and 2004 Icelandic media did little, however, to sustain different or contrasting visions of the future that genetics will be part of. The Icelandic media mostly served as an amplifier for technology optimism, market optimism and medical optimism, neglecting the more complex epistemological, cultural and ethical aspects of genetics. After the decline of the heated but substantially "thin" HSD debate, doubts, uncertainty and ignorance have largely been left unvoiced in the media, and so have the more controversial bioethical and biopolitical aspects of genetics. Thus, the media have not provided the conditions for a sustained and well-informed public deliberation about the political and institutional governance of genetics-related issues in Iceland. In fact, there has been a remarkable lack of debate about the implications that the thriving genetic research in the country may have upon healthcare and society in general.

The only genetics-related field where different futures are projected in Icelandic media is that of economy; and in this area the media typically convey a sense of fascination or thrill regarding the entrepreneurial bravery of Decode and the profit that can be made, combined with uncertainty whether the company will indeed succeed in turning "scientific discoveries into business opportunities" (Viðskiptablaðið 2004). This particular combination of optimism and acknowledgement of uncertainty is worth noticing: the forceful assertion that genetic technologies will improve health, and that struggles among biotechnology companies is the means of choice for developing such technologies, makes it logical that the crucial uncertainty to be analyzed is whether Decode will be among the champions in the competition and make a fortune on the "health market". In a discourse of monetary gain and loss, fundamental questioning of the epistemological, ethical and cultural implications of genetics has little press appeal.

Table 2 lists different benefits that players on the Icelandic scene may receive if optimism about Decode's research prevails. In principle, everybody involved may take interest in any of the benefits listed in the table, and other benefits are of course also conceivable. In any case, expectations of benefits such as those listed are probably among the reasons why different agents support hype and wishful thinking in the Icelandic news media, either by direct contribution or through failing to promote contrasting examples and competing visions of genetics.

There is a reason to believe that the confidence and knowledge needed for critical questioning of genetics in the media is especially difficult to achieve in Iceland as the knowledge sector of Icelandic society is small and vulnerable. Scientists willing to offer second opinions are probably hard to come by, and it is unlikely that journalists writing about genetics in an environment where science reporting is a non-existing specialty feel comfortable pursuing complex moral and epistemological issues without the support of experts. Furthermore, we find it likely that Icelandic journalists – like many others in Iceland – have invested hope in the optimistic account that Decode's research is drawing worldwide admiration and making the tiny nation of Icelanders better known to the rest of the world: How sweet the glory when a new generation of blockbuster drugs and predictive technologies from Icelandic company Decode have come in worldwide use! Nevertheless, for reflexive evaluation and legitimate political processes to prevail in the field of human genetics, society needs balanced information and discussion in the public sphere. Although optimism is needed if science is to make progress at all, it must be accompanied by adequate information, acknowledgement of uncertainty and ignorance, and critical awareness that in a pioneer era of trial and error there are many potential futures, not all of them equally bright. The present study indicates that Icelandic society is far from sustaining such an awareness.

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Notes

1. In the final coding framework the following definitions were used: *(1) Thematic focus.* Business: Finances, contracts, employment and market issues. Science: Research activities, plans and results, including research ethics issues. Health: Genetic components of disease and the impact of genetics on healthcare. Other: E.g. charitable and public relations activities. *(2) Evaluative framing.* Positive: Favourable impression given of Decode or genetics in general. Negative: Unfavourable impression given of Decode or genetics in general. Neutral/balanced: Issue presented matter-of-factly, without obviously giving a positive or negative impression of Decode or genetics in general; or positive and negative elements discussed without the one being presented as clearly superior to the other.

2. Items not related to Decode amount to 8.4% of the total material only. In items related to *UVS*, a company working on cancer genetics which has now been taken over by Decode, and in items concerned with university research, scientific and national advantages as well as the potential for improved healthcare are highlighted in the same manner as in Decode items. A TV interview with Nickolas Short, former editor of *Nature* on the occasion of a conference arranged by *UVS* in 2000, illustrates this. When asked how biotechnology would be of use in the fight against disease and what role Iceland could play, Short answered without reservation: "The entire human genome has been mapped. The technology is improving faster than ever before. [. . .] Cancer is a very challenging task, where Icelanders can get unique results" (RÚV 12 July 2000).

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