

# Managing HuGE Expectations: Rhetorical Strategies in Human Genome Epidemiology

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This paper examines the rhetorical processes by which spokespersons and practitioners of human genome epidemiology (HuGE) try to articulate and legitimate their methods and approaches, while solidifying their future in American public health as a discipline at the intersection of epidemiological and genomic discourses. Based on works within the 'dynamics of expectations' this examination seeks to expand on the temporal understanding of expectations by identifying the specific rhetorical strategies used to manage emerging techno-sciences. Understanding such specific strategies is necessary for analysts working around fields of science that are highly contested and lodged in a prospective discourse, such as the climate sciences, information technologies, and other areas of biotechnology.

*Key words:* expectations, rhetoric, human genome epidemiology

Ultimately, in order to fulfil the promise of the Human Genome Project in improving health, multidisciplinary medical and public health approaches are needed. At the core of these approaches is the simple question: "what are the risks?" followed by the question "what to do with numbers once you get them?" To get there, we have a HuGE map to follow (Khoury *et al.*, 2004)

Human genome epidemiology, or the clever acronym of HuGE, is being positioned by some of its practitioners as the hopeful future for the field of epidemiology, and the emerging scientific specialization that is necessary for the trans-

lation of information gleaned from the Human Genome Project (HGP) into health benefits (Khoury *et al.*, 1997). Given the scope and scale of the HGP - the thirteen-year endeavour included eighteen countries in which the costs of the primary contributors located in the USA ran over \$3 billion (Department of Energy, 2005) it is essential that we examine the formation of the scientific specialization that is emerging as its next crucial step.

Despite the continuing advances in human genetics spurred on by the Hu-

man Genome Project, numerous gaps exist in the amount and quality of population-level information for most of the newly discovered genes. Human genome epidemiology (HuGE) studies are needed to measure the prevalence of gene variants in populations, identify gene-gene and gene-environment interactions, quantify the impact of gene variants on the risk for disease, and evaluate and monitor the increasing use of genetic tests. (Marks and Yoon, 2002)

Despite their related nature, HuGE is a new and different beast. Unlike the HGP, human genome epidemiology is not a research project, nor does it have a definitive beginning or end. HuGE practitioners and spokespersons face challenges associated with emerging specializations or disciplines rather than those organizational issues typical of research projects<sup>1</sup>, and are concerned with different scientific problems (i.e. actually making sense of the massive amounts of sequenced data provided by the HGP). This combination of lofty associations, novelty and distinctiveness provides cause for HuGE's critical investigation. Moreover, critical examination is necessary because HuGE is emerging in a period in which medical applications of genetics are coming under increasing scrutiny and expectations surrounding them are being seriously re-examined.

In order to make sense of this new phase in the delivery of genetic health, and to make use of the lessons from our recent past that have demonstrated the need for a critical examination of scientific promises, we require an analytical approach that focuses on the dynamics of expectations. Biomedicine is not unique in exhibiting these dynamics; rather, expectations and promises have

come to be regarded as a general feature in strategic sciences (Van Lente, 1993: 87). In pinning down the role and effects of expectations we are able to broaden our more general understanding of how techno-sciences come into being. If a desire exists to understand these dynamics in a way that is not overly technologically deterministic, then it is essential that we give credence to the language strategies, or rhetorics, that are instrumental in enrolling actors in emerging disciplines, legitimating research trajectories, and getting scientific work done (Van Lente, 1993: 187).

### **Research Objectives and Methods**

This paper examines the rhetorical processes by which spokespersons and practitioners of human genome epidemiology try to articulate and legitimate their methods and approaches, while solidifying their future in American public health as a discipline at the intersection of epidemiological and genomic discourses.

In the case of HuGE, it is shown that these rhetorical processes are based in a temporally structured discourse – with spokespersons either negotiating the past expectations or constructing a bright future around new ones. The nature of these expectations are not only based in the hope that HuGE provides for the future of a genetic approach to public health, but also in the validation of HuGE as a scientifically legitimate line of investigation for epidemiology and in the enrolment of professionals to take up these specific practices. Due to the centrality of these temporally organized rhetorical strategies, it is impossible to understand HuGE without an under-

standing of the dynamics of expectations. One of the possible sites for an investigation of these dynamics, as well as the management of rhetorical strategies in securing a future for an emerging techno-scientific discipline, is in the content of key articles and editorials in scientific journals and books. It is in these texts that the 'public face' of science is to be found, in which spokespersons and champions of emerging specialization can openly deploy visions statements and expectations for the rest of the scientific community to digest or reject.

This article draws on findings from recent social science research exploring the production and organisation of post-HGP public health genetics located primarily in the United States. Presenting an examination of relevant epidemiological journals on the web of science using search terms human genome epidemiology, as well as molecular epidemiology and/or genetic epidemiology coupled with the human genome project. The research led to the identification of Dr. Muin Khoury as the central spokesperson for HuGE. This was followed by research into some of his articles that carry key expectations surrounding HuGE, as well as work that cite the articles that carry similar vision statements and expectations. This was coupled with an analysis of the website for the Office of Genetics and the Prevention of Disease (OGPD), at the Centers for Disease Control and Prevention in the United States (CDC), to which Khoury is the first, and to date, only director (Centers for Disease Control, 2004).

To frame the discussion, a short elaboration will be carried out on recent literatures in Science and Technology

Studies (STS) on the 'dynamics of expectations', particularly in the work of Van Lente (1993; 2000) and Brown and Michael (2003). A brief history of the contested nature of epidemiology will then be given to demonstrate the susceptibility of the field to the expectations and promises of HuGE and its molecular and genetic epidemiological predecessors. It is because of the future orientation in which HuGE is positioning itself, coupled with the contested history of epidemiology, that an examination of the rhetorical strategies used in managing expectations is, I argue, so crucial.

The central section of this paper will examine the way practitioners and spokespersons manage expectations surrounding HuGE, especially in order to rescue HuGE itself from accusations of failed promises of future expectations. While a focus on rhetorical strategies within scientific texts is required in order to understand the way in which expectations are positioned and managed in emerging techno-sciences, it is recognized that such an application does lead to some methodological problems in terms of conceptualizing if and how expectations are internalized by members of the scientific community, and consequently the measurement of the relative weight and power of such rhetorical strategies. These caveats are discussed in more detail in the concluding section that will address some of the deficiencies of this approach that connect more generally to the study of language and rhetoric as central analytical categories within the STS discourse.

## Approaches to Techno-Scientific Expectations

In recent years scholarship has been accumulating on how techno-sciences emerge, and particularly, how they are shaped by expectations and rhetorical strategies (Brown *et al.*, 2000; Brown and Michael, 2003; Martin, 2001; Hedgcock and Martin, 2003; Van Lente, 1993; 2000). Harro Van Lente (1993; 2000) writes of the “dialectic of techno-scientific promises” and demonstrates the rhetorical processes by which these promises can be transformed into requirements. Van Lente (1993: 130-131) has shown that when the potential of a techno-science is coupled with perceived desirability or necessity of such developments, then the outcome can be one in which the technological promise is moved into a position that demands actions. For Van Lente, techno-science emerges dialectically in a benign tension between future promise and present requirement. While such rhetorical approaches are not new to science, in novel areas of innovation promises abound as firms and governments attempt to forecast, foresee, and foretell new and promising research areas for investment (Van Lente, 1993: 132). In addition to the role that promises play in this dialectic is the concomitant relationship that has emerged between notions of progress and science and technology, to the point that techno-sciences have become “engines of futurity”. The relationship between the future – as a conquerable temporal domain – and techno-science is a deep one, which demands unpacking.

Despite the potentialities for mobilization that these dialectics exhibit, all promises that are made are rarely ful-

filled in the way they were originally envisioned. As a result of copious disappointments in the emergence of various techno-sciences, theorists such as Brown and Michael (2003) have examined how such promises – expectations is their preferred term – are managed by those near the site of knowledge production. In their “sociology of prospective techno-science” the authors argue actors’ recollections of past memories of the future of a techno-science (what they term “retrospecting prospects”) change over time (Brown and Michael, 2003: 4). Therefore, an actor – who at one point in the past was extremely optimistic about an emerging techno-science – will recollect those expectations in very different terms and in fact reconfigure them in the present to meet new and future demands. Further, they assert that expectations of a current techno-science can be managed by way of rhetorically *distancing* it from historical examples of other prospective techno-science (a process they term “prospecting retrospects”). The authors’ find that while some techno-sciences might be related or similar (as is in the case of the regenerative goals of biotechnologies, such as xenotransplantation and more current stem cell innovations) practitioners near to the site of the current knowledge production often choose to disassociate past prospects from their own current prospect (Brown and Michael, 2003:11). This hopeful future is maintained – the authors argue – so that a present day or ‘real time’ unstable network of actors and practitioners can be more effectively mobilized around a set of emerging scientific practices (Brown and Michael, 2003: 15).

Brown and Michael’s analysis is suited

for critically engaging expectations surrounding other emerging techno-sciences, especially human genome epidemiology. HuGE has been proceeding in fits and starts, and those near the site of knowledge production structure their approach in a discourse of future orientation premised in hope. As a result, the analysis taken-up here will be in-line with the tactic Brown and Michael suggest of examining how practitioners and spokespersons manage the expectations around emerging techno-sciences through time, yet the focus here will be on the specific rhetorical strategies used to attain such goals<sup>2</sup>. It is the case that excellent work has been done in the analysis of rhetorical strategies in the construction of scientific text (namely Myers, 1985), and while it would be valuable to explore in more detail how the scientific arguments for HuGE are constructed, it is simply not within the scope or scale of this paper.

It should also be noted that rhetoric, and the broader use of language, is but a part of the process by which some techno-sciences live and others die. As Brown *et al.* (2000: 3-4) have pointed out, there are also issues of practice and materiality at work in the construction process; simply because a rhetorical device is deployed, technological advancements and scientific breakthroughs are not guaranteed to take place. With that in mind, we are provided due cause for examining language and rhetoric in scientific discourses.

Language, of course, is by definition part of the common background in which particular instances of technical change are embedded. Moreover, the advantage of studying language use over studying convictions or particular

beliefs is that the former is accessible to the analyst, while beliefs and convictions are notoriously difficult to examine. *The question, then, is what kinds of language strategies are involved and how these affect the fate of technical futures.* (Van Lente, 2000: 44, my emphasis).

In basing this analysis in Brown and Michael's (2003: 3-4) premise (i.e. that expectations of those near the site of knowledge production change through time to rhetorically secure the future for the techno-science they champion) the goal here is to use HuGE as an opportunity to answer Van Lente's call in identifying and explaining specific language strategies and their effects on technical futures. Using HuGE as a case for this task is justified not simply because it converges with the processes by which many other emerging techno-sciences deploy expectations to solidify their futures. In a more useful manner, HuGE acts a unique window into understanding the life-cycle of prospective techno-sciences because those near the site of knowledge production are now making use of specific language strategies in order to *manage* earlier expectations.

### **Epidemiology: Recent Past and Present**

The disciplinary history of epidemiology is a storied one, whose demarcation activities, boundary work, and desires for scientificity have received excellent examination of late by Amsterdamska (2005). Epidemiology has historically been occupied by various methodological approaches whose developments have been influenced by "shifting institutional location and uncertain status within medicine and public health"

(Amsterdamska, 2005: 44). Traditionally, epidemiology has not been an experimental or laboratory based science; instead its' convention has been to rely on statistical association, modeling the spread of diseases, or calculating risk factors (Amsterdamska, 2005: 18). As a result, "epidemiologists' ideas about what it means to be a science and how to demarcate epidemiology changed several times" during its history (Amsterdamska, 2005: 19).

Questions regarding the scientificity, preferred analytical approach, and professional status of epidemiology surfaced again, in a very public fashion, in 1995 when *Science* published a special report suggesting that epidemiology had "faced its limits" (Taubes, 1995). This, now widely cited<sup>3</sup>, special report was a reflection of something of a crisis within epidemiology suggesting that under the current "risk-factor" direction epidemiologists were producing contradictory findings: "in January last year, for instance, a Swedish study found a significant statistical association between residential radon exposure and lung cancer. A Canadian study did not" (Taubes, 1995: 164). Not only were many of the products of epidemiological studies contradictory, but fundamental methodological problems associated with biased sampling and hidden risk variables, or confounding factors, were also being raised (Taubes, 1995: 167; Susser and Susser, 1996). Further, critique from within the discipline also pointed to the failure of epidemiology to identify pathogenesis, or the sequence of events that leads to the development of a disease.

Epidemiology has become a set of generic methods for the *measurement* of disease occurrence, and there has been

a concomitant lack of distinctive theory to permit an understanding of population pattern of disease occurrence... Most modern epidemiologists still do studies in populations, but they do so in order to study decontextualized individual risk factors, rather than to study populations in their social and historical context (Pearce, 1996: 67, my emphasis).

Contradictory findings and methodological critiques lead to confusion in the media responsible for communicating the message of epidemiologists to the broader public, as well as uncertainty for state officials who were supposed to create health policy based on conflicting explanations of the "real" cause of disease (Taubes, 1995: 164).

While it is the case that tensions between different approaches often exist within scientific disciplines, rarely is it the case that the actual future and utility of an entire field is called into question as was seen with epidemiology. It was this fundamental and deeply rooted disciplinary uncertainty regarding the most appropriate, and most scientific, way of carrying out epidemiological studies that opened up the field to a range of possible new ways forward. This contested nature of epidemiology also produced a gambit of expectations about what various approaches offered as the future for the field. Two of the approaches that were pushed into the field's spotlight by their spokespersons were the predecessors of HuGE – molecular and genetic epidemiology. While HuGE is an emergent research endeavour that is primarily located within its 'birthplace' of the Centers for Disease Control and Prevention (CDC) in the USA, molecular and genetic epidemiology have longer disciplinary histories

and have been practiced in broader national contexts.

### **Expectations of Molecular and Genetic Epidemiology**

The appearance of disarray within epidemiology that was noted in the mid 1990s (Taubes, 1995), coupled with the relative novelty of molecular and genetic approaches (Khoury, 1999: 72), suggests that lofty expectations were needed in order to secure a future of the discipline. Brown and Michael (2003:16) have argued that, “radical discourses about the future are indicative of the emergence of networks (new relationships) and activities (new ways of doing things)”. As a result, in order to stabilize its practices, mobilize practitioners behind a specific methodological approach, and thus secure a future for the discipline; molecular and genetic epidemiological spokespersons deployed a series of expectations about what their preferred future would entail.

Specifically, molecular epidemiologists were claiming that their methodological approach offered increased ability to locate causes of disease, or what they call specificity (Trichopoulos, 1996: 4-5). By analyzing molecular causes for a disease, or biomarkers, at the population level molecular epidemiologist argued that risk-factors could be more accurately identified. Further, molecular biomarkers were claimed to represent risk-factors that were stable over time (i.e. not likely to change or fluctuate the way environmental risk-factors might be claimed to do) (Trichopoulos, 1996: 4-5). By framing their methodology in terms of specificity (by way of biomarkers) and persistence, spokesper-

sons for the molecular approach to epidemiology essentially claim to offer increased scientificity because their findings are being presented as more accurate and reliable – the defining features of scientific measurement. In contrast to convention, this molecular approach grounds epidemiology in the laboratory, which in combination with claims to increased scientificity, creates expectation for a positive future for the field for disenchanting practitioners to flock to.

Further, expectations and increased scientificity are aggrandized by way of the mobilization of technological advances and the breakthrough of the Human Genome Project.

The revolution in molecular biology, which began several decades ago, has led to many incredible scientific advancements, particularly the identification of genes known to contribute to the occurrence of human disease. *The recent availability of genetic maps of highly polymorphic loci that span the human genome, as well as the evolution of statistical methods and computer technology*, have provided important new tools for studying the genetics of chronic diseases (Dorman, 2000: 1261, my emphasis).

The appeal of increased techno-scientificity, it can be argued, works to create a sense of potential for the field, a mandate for further epidemiological studies for future epidemiologists to partake in.

Related to the prospective specificity and persistence of biomarkers, as well as the enrolment of the HGP for understanding disease, is the claim that the molecular approach will work towards the unveiling of disease pathways and mechanisms. As two practitioners argue, “earlier predictions in rapid advances in the control of disease are unlikely to be

seen” (Smith and Ebrahim, 2001: 100). The same authors, however, also state: “However a greater understanding of the mechanisms of disease development and thus the development of therapeutics may be anticipated” (Smith and Ebrahim, 2001: 6). This offer represents not only an increased understanding of *how* diseases operate, but it is an offer of treatment. Framing the molecular approach in such a way – the path to potential treatment for disease plagued individuals – is perhaps the most legitimating claim, the most powerful expectation that a health related science can disseminate for the mobilization and enrolment of practitioners.

### **Negotiating the “Past”: A Relentless Battle With Time and Expectations**

HuGE and its molecular and genetic predecessors are clearly replete with expectations concerning their place in the future of epidemiology, as well as their role in translating advances in genetic information into genetic medicine and public health. Be that as it may, what happens when the “map” to the bright future, which has been constructed by spokespersons, begins to be seen as leading practitioners astray from their goal of improved public health?

As we have seen, the claim that HuGE spokespersons and practitioners are putting forward is that HuGE will be successful where other epidemiological approaches have stumbled because it has the breakthrough of the sequenced human genome, which previous epidemiological approaches lacked. The claim is that epidemiology will therefore move away from the reductionism of simplistic and misleading gene-disease associa-

tions, and instead look at the entire genome and move towards an examination of gene-gene and gene-environment associations. Muin Khoury, HuGE’s central spokesperson, makes such a claim consistently, and does so with support from leading geneticists.

Peltonen and McKusick outlined the progressive shifts occurring in several Areas... in post genome discovery, there will be an increasing shift from studying genetic diseases to studying all diseases, assessing gene products (proteomics), from mapping and sequencing to discovery of genetic variants, from studying single genes to multiple genes, from studying gene actions to studying gene regulations, and finally from diagnostic testing to testing for susceptibility. Epidemiologic methods should play a role in all these areas (Khoury *et al.*, 2004).

However, the field has had to admit that regardless of this breakthrough, scientific novelty is hard to come by, and old habits and research strategies are hard to break. As of 2003, leaders of the emerging field of inquiry found that “in virtually all of the reviews [of HuGE studies], it was concluded that there was no clear immediate public health application of the data” (Little *et al.*, 2003: 668). A couple years earlier a study that was carried out regarding epidemiological publications that would fall under the umbrella term of HuGE showed that

[o]f the 2042 published articles, most reported only on population prevalence of gene variants or simple gene-disease associations (82.0%) while 14.5% integrated the study of interactions (gene-gene and gene-environment) and only 3.5% dealt with evaluation of genetic tests (Khoury, 2002: 297).



Despite this self-acknowledged absence of applicability, and in the face of reports from within the field of the continuation of a narrow research agenda, data gathering persists and the evolving field of inquiry continues to try to articulate and legitimate its methods and approaches, while solidifying itself as a discipline at the intersection of public health and genomic discourses.

How then are expectations for epidemiology managed, given the hurdles that have been identified by spokespersons and practitioners near the site of HuGE knowledge production? Spokespersons must engage in a never-ending negotiation process to direct the recent past as it continuously emerges.

### **Specific Language Strategies and Rhetorical Deployments in Managing Expectations**

In the course of time, expectations that have been used to try and colonize a future for a techno-science can be juxtaposed with the self-reported state of the scientific art, and in doing so an evaluation of the progress of those expectations can be made. However, as we have seen in the above case of HuGE, drastic scientific advances are hard to come by. In order to protect an emerging field from scrutiny, or claims of failure, spokespersons and practitioners will often deploy language strategies in order to guard their envisioned techno-scientific future. In the following section I identify a series of claims from within the HuGE literature that – I argue – not only work to report on the status of the emerging science, but also to manage the expectations that had already been deployed in the process of colonizing the future

of epidemiology. It should be noted that by identifying these statements as language strategies in negotiating the future *and* past of HuGE I am not positing that Khoury and his colleagues are trying to trick scientific audiences or that they are being dishonest; rather, the goal here is to show some of the rhetorical tools that can be used to stabilize techno-scientific futures in the face of elusive expectations.

### *Position Yourself at the Beginning of a Long Road*

As concerned as they appear with translating advances in genomic research into public health action, HuGE practitioners argue the field of study is in its infancy. Further, while the HGP is officially “finished”, genomic researchers can be seen to have their plates full with gap filling, fine-tuning, and other research priorities that Francis Collins and colleagues (2003) have recently laid out for them. As one of the leading entrepreneurs of HuGE points out,

[o]verall, the task of characterizing the human genome is at the beginning. The concern that the potential value of this exercise to public health has been exaggerated or that the amount of time needed for information relevant to public health to be accrued has been underestimated underlines, more than ever, the need for integration of evidence from carefully conducted population-based studies (Little *et al.*, 2003: 670).

Due to the fact that HuGE practitioners place themselves at the commencement of their tasks, or at the “beginning” of a long road, the hurdles that have, and continue to be, experienced in translating the HGP into practical public health

information can be managed. Practitioners and spokespersons can be seen to be backtracking on previous projections, and attempting to hedge their bets between what they have claimed to be able to deliver and the difficulties they are facing in the process of delivery. This is a rhetorical strategy, and it is directed at maintaining the confidence of the scientific community. Nevertheless, the central force in the above statement lies in its ability to mobilize practitioners and stabilize them around a specific set of practices. As practitioners and spokespersons argue, simply because the field is at the beginning of a long road does not mean that the undertaking should be abandoned, on the contrary, “more than ever, the need for integration of evidence from carefully conducted population-based studies [i.e. HuGE]” is required (Little *et al.*, 2003: 670). Here the slow start of translating the HGP into valuable HuGE knowledge is not seen as a downfall, but rather as a rallying cry to mobilize practitioners around a specific set of epidemiological practices that are characteristic of HuGE.

#### *Claim you are Dealing with Increasingly Complex Issues*

A strategy related to positioning a techno-science at the beginning of a long road is to argue that the undertaking is just a little more complex than originally thought. Not only can this be seen as a refusal to black-box the techno-science in question, but as Brown and Michael (2003: 10) point out in their examination of expectations, “...memories are differently used in the constructions of future expectation”.

As Gwinn and Khoury demonstrate,

until recently, research on genetic factors in disease has been limited almost exclusively to analysis of single, highly penetrant gene variants (e.g., BRCA1), which because of their rarity account for only a small proportion of cases of common diseases. The remainder likely result from complex gene-environment interactions that remain poorly understood. Although methods for studying these interactions are still at an early stage of development, family history provides another potential measure of shared genetic risk, as well as the influences of common diet, behaviors, and other nongenetic factors (Gwinn and Khoury, 2002: 411).

Elsewhere it has been argued that black-boxing a techno-science works towards its legitimization because the knowledge contained within the “box” gains protection from closer scrutiny (Latour, 1987: 23). Since Khoury is addressing an epidemiological audience with high levels of scientific sophistication black-boxing has not been a technique easily employed. In refusing to black-box the HGP and arguing that the undertaking is more complex than initially conceived, it could be argued that the practitioners and spokespersons of this evolving field of inquiry attempt to retain their scientific integrity, the respect of the scientific audience that they are trying to mobilize, and to protect genetic breakthroughs and expectations from criticisms outside of the sub-discipline of HuGE. Had spokespersons tried to paint a rosy picture for genetic public health in light of an initially slow start, then they could have been framed as unrealistic, or worse, untruthful. Such a stigma would be incredibly damaging for a young approach that is continuously trying to mobilize and legitimize support amongst practitioners.

A further reason why the above quote is a strong rhetorical deployment in response to initial problems is to be found in its simultaneous evocation of a positive future. By drawing on, and subsequently distancing itself, from a history in the field that only investigated “single, highly penetrant gene variants (e.g., BRCA1), which because of their rarity account for only a small proportion of cases of common diseases” (Gwinn and Khoury, 2002: 411), the spokespersons can be seen to be “retrospecting prospects” of previous genetic epidemiology (i.e. recalling the prospects of the approach differently because of the way expectations were or were not fulfilled). In subsequently claiming that elusive gene-environment interactions might be addressed by way of family history, Gwinn and Khoury can be seen to be “prospecting retrospects”. In juxtaposing past undertakings with current directions and suggesting that the path now being followed holds more promise, the complications of previous, yet related, research can be controlled and a bright future for current research can be created and sustained. By positioning the field as honest about its difficulties, and yet at the same time identifying some of its potentialities, spokespersons are pointing to a promising and increasingly scientific direction for the field that they hope their audience will be interested in taking part in and furthering.

*Deflect the Blame onto the Media*

When a techno-scientific direction is not perceived to be delivering on earlier expectations, rhetorical strategies can be seen to place blame on an outsider – namely the popular media for misconstruing

these expectations and misrepresenting scientific claims. As expectations and social pressures mount in anticipation of the benefits of the HGP-based health products and the prevention of disease, HuGE spokespersons employ rhetorical strategies which blame the media and argue that it was they who claimed that epidemics could be impeded in the first place. Scapegoating the media should be seen as an effect of these rhetorical strategies rather than their premeditated aim. As Brown has pointed out, “indeed, it is the ambiguity surrounding who is responsible for the social scripting of breakthrough that allow scientific and journalistic actors to exchange ideal reporting identities and conventions when it suits them to do so” (Brown, 2000: 94). We can see this exchange of “ideal reporting identities” at work in this excerpt from Khoury.

Indeed, we are confronted daily with one or more new gene discoveries claimed to be associated with increased risk for some disease and promising a sweeping change in the diagnosis, treatment or prevention of that condition. Table 1-1 shows a sample of stories from web-based headlines. These titles illustrate that gene discoveries involve a wide variety of diseases not normally considered “genetic”, and often include information about interactions with non-genetic factors such as cigarette smoking and drugs. Although gene discoveries generate excitement and expectations, their contribution to disease prevention is not clear (Khoury *et al.*, 2004).

In framing lack-lustre results (e.g. “Although gene discoveries generate excitement and expectations, their contribution to disease prevention is not clear”) of the HGP and HuGE as being sub-standard due to the irresponsible crea-

tion of unrealistic and unscientific expectations on the part of the media, problems and concerns are diverted from the breakthrough and chosen techno-scientific direction themselves, to the integrity and credibility of popular and scientific journalism. In doing so the rhetorical weight of expectations can be potentially preserved and the positive light that the techno-scientific direction may have once enjoyed has the chance of being re-established.

### *Point to Commercial Pressures for Creating Unrealistic Expectations*

Alongside the media, industry and commercial pressures more generally, represent other groups who are effectively scapegoated in the process rhetorically rescuing expectations. As Khoury demonstrates:

the rapid expansion in the number of reported gene-disease associations may lead to pressure to develop commercial tests before validation of research findings (Khoury *et al.*, 2004).

Unfortunately, what happens after a new gene discovery is announced is often a haphazard mixture of scientific excitement, heightened public awareness and commercial interest in developing and marketing genetic tests. This is exemplified in the media coverage of the 1997 publication of an association between familial colorectal cancer in Ashkenazi Jews and the presence of a mutation in the APC gene... Although this study needs further replication and its implications in medical practice are far from clear, it does illustrate the mounting pressures for a rapid transition from gene discovery to integration in clinical practice, which could result in the premature development and offering of genetic tests (Khoury, 1999: 71).

Here we see that the pace at which health benefits should flow from HuGE translations of HGP data is being defended by the spokespersons. While this defence can be seen as the aim of this rhetorical strategy, the effect ultimately scapegoats industry and commercial pressures. HuGE practitioners are being depicted as potential victims of commercial interests and pressures, and by suggesting the need for further replication of relevant studies; HuGE is presented as an independent and scientifically-grounded undertaking that will not bend in the face of industrial pressures to produce hurried results. By presenting industry as chiefly concerned with products and market success, the professional prestige of the discipline can be strengthened as practitioners and spokespersons are framed as the defenders against such interests.

Deflecting frustrations onto commercial interests as to the pace at which health benefits are supposed to flow from HuGE translation practices of HGP data effectively reinforces an unnatural distinction between the “public” and “private”, which Brown and Rappert (2000) have shown to be more complex, convoluted, and interdependent than these pure terms might suggest. Side-tracking attention onto commercial pressures can obfuscate the fact there are intense financial implications involved in the HGP and subsequent gene identification and characterization processes. In evoking these codes of “public” and “private” spokespersons can frame HuGE as operating solely on behalf of the “public”, and therefore it is argued that careful and meticulous work must be carried out in order to assure the safety and health of the people. A “pub-

lic-based” approach to HuGE practices has the potential to create a space in which the expectations of the translation of the HGP could justifiably proceed at a cautiously slow pace.

*Ethics Complicate the Translation of Data to Health Practices*

Related to the scapegoating of industry in the defense of the pace at which health benefits flow from HuGE and the HGP is that of (bio) ethics. While ethical issues certainly deserve and require attention, practitioners can also use them as a rationale as to why health related technologies and information are only slowly making themselves available.

Policies regarding genomic testing require ongoing evaluation in the evolving social context of ethical principles, legal requirements, and social concerns. In particular, principles of population screening – the traditional domain of public health – will require rethinking in the age of genomic medicine. (Gwinn and Khoury, 2002: 410)

The suggestion here is not that HuGE practitioners do not take ethical concerns seriously, nor is it that they use them as a front to buy more time for their research; rather, the claim is that ethical concerns are one of the many elements that complicate the translation of genetic information into public health practices, and that HuGE practitioners want the public and other epidemiologists to know that they are indeed taking these issues into consideration. In demonstrating that the field is concerned with, and addressing, ethical issues the professional status of the practitioners is re-enforced. By being shown to be concerned and moral human be-

ings, scientists working in genetic areas can be seen to re-establish their professional and moral prestige, which has undergone damage in an era plagued with reports and investigations of scandals and conflicts of interest<sup>4</sup>.

*Claim Slow Practitioners’ Response to the Challenge*

Arguably the ideal rhetorical deployment for rescuing lofty expectations is to combine the complications of the techno-science with the scapegoating of actors that are outside the knowledge production process. Such a strategy would prevent alienating epidemiological practitioners, and as mentioned, concurrently build the aura of professional prestige for the discipline. However, as the case of HuGE shows, sometimes it is necessary to identify problems that lie at the centre of the knowledge production process in order to protect the breakthrough from closer scrutiny and maintain the prospects of positive futures that it provides for the technoscientific direction. We see Khoury placing responsibility for mediocre results and sluggish application directly on the practitioners and their ways of working, which represents a risky rhetorical move.

In an analysis of the epidemiologic quality of molecular genetic research, Bogardus et al. used seven methodological standards to evaluate the quality of studies in four mainstream medical journals. They found that in spite of the major molecular genetic advances, 63% of the articles did not comply with two or more quality standards (Khoury, 2002: 298).

While technical advances continue to increase the capacity of epidemiologic

studies to carry out large-scale genotyping and measurement of biomarkers, the ability to assimilate, synthesize, and interpret the data has not yet fully caught up. New methods are needed if these data are to be translated into useful information for predicting disease and guiding interventions (Gwinn and Khoury, 2002: 410).

Positioning slow developments in genetic public health as a result of practitioners being slow in taking up the challenges is a similar rhetorical deployment to the positioning of HuGE at “the beginning of a long road” or that “the issue is a little more complex than we originally thought”. As Van Lente (1993:125) has argued, such statements are not meant to discourage the practitioners, or other audiences, that might be involved in the advancing the techno-science in question; rather, such statements are part of his “dialectics of promising research”. This rhetorical device is structured to point to the promise that the techno-scientific direction offers, but simultaneously argue that such promise will not be realized without increased methodological fastidiousness and professionalism. What is particular about HuGE’s rhetorical deployments of this sort is that they seem to be targeted more directly at the practitioner than sounding the traditional call for further research. Such defiance of the audience that you are actively trying to mobilize can be seen as a risky move, and might lead us to question the motivations for such a strategy. HuGE deployments might therefore be seen as a kind of “tough love” technique, which posits the meticulousness of future research as a challenge to practitioners, but I would suggest that it serves an additional purpose.

By positioning slow developments of applicable epidemiological knowledge as the result of the “quality” of the scientific studies being done (Khoury, 2002: 298), and of the in-“ability” of practitioners and methods to “catch-up” to the pace at which data is being produced (Gwinn and Khoury, 2002: 410), spokespersons are effectively protecting their vision of the future of public health and the role that their techno-science might play in that vision. By pointing to the human component as the source of the problem, the techno-scientific breakthrough (i.e. the HGP) that is instrumental in creating a prospective future for the discipline can be preserved. A structural-functionalist might argue that while the mobilization of practitioners to take-up HuGE practices is key for the future of the discipline, they are basically bodies that come and go; whereas there is only one HGP. As a result the preservation of the structure of techno-scientific direction (of which the HGP is a corner-stone) is of greater importance than the possible alienation of a few cogs in the wheel. Again, the risk involved in this deployment is significant.

#### *Problems Rest in Poorly Designed Information Infrastructure*

Identifying the neglect of practitioners and shortcomings of methods is not the only rhetorical particularity that HuGE exhibits while its spokespersons manage the expectations on which its discipline is based and future rests. Spokespersons can also be seen to argue that some expectations have indeed been met, in fact they have been fulfilled to the point that the problem rests in the poorly designed infrastructure for the masses of informa-

tion that are been produced.

There is also the challenge of the ever-increasing number of human genome epidemiology studies... Therefore, integration of evidence will become increasingly important as a means of dealing with potentially unmanageable amounts of information (Little *et al.*, 2003: 670).

Where information [on population-based data] does exist, it is scattered across the Web on sites for government agencies, universities, private companies, nonprofit organizations, and others. No focal point or central repository exists today for data and resources on genetic epidemiology (Marks and Yoon, 2002).

We continue to see the dialectic of promise at work in these above rhetorical deployments. In suggesting that the problem rests not with HuGE studies *per se*, but with what is done with them and where they are kept, these rhetorical deployments can thus be seen to compensate the practitioner for work well done, while simultaneously calling for increasing mobilization to improve information infrastructure and synthesis activities, and secure new funds.

#### *Create Fear and Urgency and Re-issue Promises*

The importance of integrating “potentially unmanageable amounts of information” (Little *et al.*, 2003: 670) through infrastructure ameliorations is taken to the next rhetorical level as HuGE practitioners create a sense of fear and urgency within the discipline. The claim is that without a clearly articulated vision and research goals for HuGE, the highly touted translation of genetic advances into public health benefits may not be

achievable. In examining the vision statements made by Khoury, it would therefore appear that a sense of fear and urgency, with regards to achieving the goal of public health, is a key unit in Van Lente’s conception of moving a forceful future from promise to requirement. We are able to see the rhetorical transformation take place in Khoury’s statements, as the early stages in HuGE’s articulation the prospects of a genetically based preventive medicine take the form of promises.

...the doctor flicks a cotton swab into the mouth of her infant son, collecting a small sample of mucus from inside his cheek... he inserts the sample into a machine, which extracts DNA from the mucus cells and compares it with the genetic material on a dime-size chip. Minutes later, a computer printer begins to spit out a list of the infant’s genes. “Your son’s genetic inheritance is generally good,” he says, “but he is somewhat predisposed to skin lesions. So starting right away, he should be protected against excessive exposure to the sun.” And the doctor warns, “he may well be susceptible to cardiovascular disease later in life. To lessen this risk, after about age 2, he should begin a lifelong low-fat high fiber diet.”

The preceding is a futuristic vision of the practice of preventive medicine in the 21<sup>st</sup> century from Time magazine. Although this scenario may seem like science fiction and is loaded with significant ethical, legal and social complications, the tremendous progress in the Human Genome Project which is rapidly unravelling our estimated 50,000 to 100,000 genes may turn this vision to reality (Khoury, 1997: 175).

However, in evoking a sense of fear and urgency, the above promise of a genetically based public health is quickly transformed into a requirement.

given the paucity of population-based epidemiologic data regarding the frequency of, and disease risks and environmental interactions for many newly discovered human gene variants, there is concern that appropriate health policy on the use of genetic tests may not be possible (Khoury, 1999: 72).

In just two years the promise that the HGP offers in transforming a “futuristic vision... to reality” is itself converted into a requirement of HuGE practices because they are currently not being undertaken to a satisfactory degree.

Therefore, what is required after of all these rhetorical deployments have been made to manage the expectations of HuGE while simultaneously (and arguably more importantly) maintaining the breakthrough as the foundation of the optimistic future of the field is cyclical: re-issue promises and re-formulate the visions of the future. It is telling to return here to one of the quotes to demonstrate the fact that HuGE has indeed been slow to deliver on requirements. Notice the re-issuing of promises that comes after the claim that data from the HGP is not in fact being used in the way that spokespersons had framed HuGE in early vision of the discipline.

...of the 2042 published articles, most reported only on population prevalence of gene variants or simple gene-disease associations (82.0%) while 14.5% integrated the study of interactions (gene-gene and gene-environment) and only 3.5% dealt with evaluation of genetic tests. Epidemiologic studies of gene-environment interaction and genetic tests are bound to increase as more genes are discovered, characterized and used to develop diagnostic and predictive tests (Khoury, 2002: 297).

The cyclical nature of Van Lente’s con-

ception of the dialectics of promises can be clearly seen to be at work in the case of HuGE as attempts are made to manage previous expectations by issuing new ones.

One could presume that if expectations are not met, trust in a techno-scientific direction could be lost. HuGE promises are, nevertheless, re-issued and expectations re-deployed so that the processes by which this emerging discipline tries to articulate and legitimate its methods and approaches, while solidifying itself at the intersection of public health and genomic discourses can continue.

### Concluding Remarks

The work carried out here has examined some of the rhetorical strategies that are built into expectations surrounding HuGE, but more importantly the way in which failing expectations are managed through time to legitimate this emerging field and mobilize practitioners has been dealt with. Based on the dynamics of expectations, this examination of HuGE has sought to expand on the temporal understanding of expectations by identifying and examining the specific rhetorical strategies used to manage emerging techno-sciences.

It should be stressed that the argument here is not that these rhetorical strategies are deployed to trick or swindle the scientific audience to which they are directed. Nor am I trying to argue that statements used by the spokespersons of HuGE are false. Rather, it is my contention that these rhetorical deployments and language strategies, which are tactics that are sometimes mistakenly seen to be outside of the normal



practice of science, serve specific purposes in terms of mobilization, legitimation, and reduction of uncertainty of emerging techno-sciences (Van Lente, 1993: 187). These tactics require constant management so that the vision of a specific future might be realized (Brown and Michael, 2003). Further, it is argued that such an understanding of specific rhetorical strategies would also benefit those analysts working in other fields that are just as highly contested in their nature and lodged in prospective discourses. The climate sciences, as well as those dealing with bio-terrorism and weapons of mass destruction (WMD), nanotechnology, stem cells research, all would benefit from a similar rhetorical examination. This is particularly true in the former cases in which expectations are constantly being managed regarding the degree to which climate change is the result of human behaviour, as well as the existence of WMDs in the Middle East.

If research were to advance in these areas, the rhetorical analyst would want to find themselves in a position to measure these expectations, or judge their effectiveness. Yet, focusing our gaze on language alone does not make the rhetorical weight of expectations easily discernable. This article has sought to identify how expectations are managed in the case of HuGE. One can ask, however, how can expectations be evaluated as successful or not by the analyst without sinking into a position of historicism that would assume the success of the rhetorical strategies solely based on the continued existence of the techno-science? Due to this problem, central questions remain to be answered in this framework: are these strategies of man-

aging expectations useful? Do they succeed in legitimating the emerging field? Are they effectively retaining a critical mass of practitioners that sit on the boundary of these activities around these emerging practices – if indeed there ever was such a critical mass to manage?

We have seen that HuGE's rhetoric is centred on positioning itself as the core science for the translation the HGP into public health benefits, but being able to couple an understanding of these expectation to the actual processes by which this translation happens would be instrumental in understanding the force, or effectiveness, of the rhetoric that is deployed by its practitioners and spokespersons. Essentially, such a task amounts to investigating the extent to which socio-technical networks do or do not develop alongside a set of expectations. Conceptualizing of HuGE (or HuGE's expectations) as a "boundary object" (Fujimura, 1992), or by tracing visions through labs, into business strategies and investment pitches, and ultimately into regulatory bio-ethical discourses – as Hedgecoe and Martin (2003) have done in the case of pharmacogenetics – the analyst could identify the actual processes by which visions shape emerging techno-science. Further, if we were able to compare rhetorical deployments of expectations from various scientific camps within the same field – for at the point of contestation over the future of a field a number of possible ways forward are disseminated – while tracing the degree to which socio-technical network form around industrial actors and ethical councils, then one could conceivably measure the success of the respective visions and language

strategies.

Other approaches to analysing expectations, such as examining peaks and valleys of biotechs within the stock market, or networking citation indexes around research programs are insufficient ways of measuring the force, or weight, of a vision because they are simply reflections of activities. Helpful as they might be in identifying the existence of expectations, these indices offer little in understanding how the analytical category of expectations functions. To be more precise, a fruitful line of inquiry should be centred on the relationship between the rhetoric contained within various expectations, and the concrete physical processes that provide an emerging techno-science a path through labs, industry and ethics to name but a few. Such an understanding would move us one step closer to a more full appreciation of how and why some emerging techno-science live and other die.

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### Notes

- 1 See Roberts (2001) for discussion on the shifting organizational history, between the Department of Energy and National Institute of Health, of the HGP.
- 2 By using the term "rhetoric" I am aligning

myself with a definition provided by Van Lente.

[Rhetoric] is not an accusation that authors use 'tricks' or that texts are phoney. Rhetorics is not swindling the audience, and scientists with diffuse promises are not cheating the government. Rhetorics can have negative connotation, but the positive meaning of rhetorics is the art of communication... rhetorics takes as the starting point the observation that authors (need to) use means to reach and convince their audience (Van Lente,1993:133).

- 3 Citation search carried out on May 23, 2004 by way of the Web of Science showed the Taubes articles to have received over 240 citations, which is enormous number for a scientific article of any kind <http://isi4.isiknowledge.com/portal.cgi/wos> .
- 4 See Greenberg, 2001 for a detailed account of scientific scandal and corruption in which ethical compromises, or blatant violations, have been made in light of potential profits.

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