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Thinking futures

Lives to come

In 1994 the late French novelist and literary translator Elizabeth Gille published a remarkable autobiography about temporal dating and anticipated death. Realising her diagnosis of terminal cancer leaves limited creative writing time, Gille pens *Le Crabe sur la Banquette Arrière*, the story of a counterpart heroine who tries to put her remaining days of declining health to the back of her mind. Friends, colleagues, family and even strangers all have other plans, however. Meaning well, they rally round this 'sick' relation offering clippings from popular magazines on the latest 'miracle remedies'; or they collect groceries suggesting she eat a 'healthy' fish diet, cook these recipes, do those exercises and so on. To her frustration Gille's heroine is reminded continuously by others how her designated sickness role, as enforced regimen of care, predates her impending death. As the author herself remarked in the advanced stages of her illness, these kinship relations are however misplaced conceptions. 'The date of your deaths remains uncertain, but mine is already set, more or less', she told close friends. 'That does not prevent me from living. Or from laughing'.[1]

It is no accident that the recent ascendancy of new genetic testing technologies primarily in the wealthiest markets of the late industrialised world has spawned both a sceptical and optimistic literature about the 'dream' of the human genome and of future 'lives to come' (see Lewontin 2000; Kitcher 1996). Scientists, the media, industry, bio-pharmaceutical companies each have various 'stories' to tell and venture interests to perpetrate about the intended benefits derived from the future creation of supposedly healthier populations. In its extreme version the vision anticipates a new era of cheap rapid genetic screening with technologies such as the DNA chip and personalised sequencing. Go to your primary care practitioner and theoretically he or she will be able to predict the probability of your getting any number of known genetic

diseases, including the common multi-factorial conditions such as heart disease, cancer and diabetes. On this basis, one's doctor could hope to recommend preventive measures before certain symptoms appear. You might be advised to come for regular check-ups, modify your diet, quit smoking, take more exercise, avoid environmental toxins and so on. Alternatively, the genetic consumer might bypass altogether the medical specialist and simply go to the local pharmacy instead. Just as 'do-it-yourself' DNA testing kits are appearing already on the market today – sold 'over-the-counter', available via the Internet or through alternative practitioners (e.g. dieticians, complementary therapists) – so in the future one might purchase one's own DNA sequence directly as a disk to self-analyse at home on one's personal computer.[2]

But would we all live longer, healthier and happier lives as a result? For the major pharmaceutical and biotechnology companies, the question may be tangential to other prime considerations. Namely, the perceived benefits of predispositional profiling turn in part on the generation of near-term revenue and the return of pharmaceutical profit for previously patented genes. The expansion of the drug market to 'pills for the healthy ill' may also precipitate onerous forms of commercial and psychological exploitation through the manipulative 'marketing of fear'; something of an antidote to the calculations of pharmacogenetics and pre-emptively tailored individual drug responses (Gilham and Rowland 2001; Moynihan *et al*. 2002; see also Davison *et al*. 1994). Such concerns tend to be countered in existing policy debate by the presumption of the active information-seeking subject and the belief that expected benefits for the populace at large turn on the individual's supposedly free choice to make responsible genetic interventions to stave off disease – this especially so against an ideological backdrop of advanced liberalism and active citizenship (for sociological critiques see Novas and Rose 2000; Koch 1999). Across these concerns one hears some research geneticists articulating the intellectual caution brake. Apparently doubtful of the predictive power of genetic medicine for the treatment of polygenic complex disorders, such developments – it is claimed – are at least some twenty to thirty years away. Of course such doubt may serve at times as another promotional strategy: the scientists' assuagement of the public's confidence. A recent refrain at academic conferences and 'science and society' events goes along the lines: 'Don't worry – things aren't running out of control – the complexity of risk quantification for common disorders is way beyond [even] us!' Meanwhile, the goal of developing a radical breakthrough (in terms of cost and throughput) in sequencing of genomic DNA has been captured in the slogan 'the thousand dollar genome' (i.e. sequencing the whole genome of an individual for about $1k in about a day). This was first

articulated at a 'visionary meeting' organised by the National Human Genome Research Institute (NHGRI) and chaired by Francis Collins in 2002.[3] In conveying these various rationalisations to the public, certain sectors of the media tend to muddle and simplify the picture with inaccurate reportage of scientists finding genes 'for' certain conditions, as if genomic-based science were fundamentally a matter of straightforward causal correlation between a gene and the phenotype, to say nothing of differences in social structure, lifestyle and environment. Through these overlapping and oft contradictory claims 'Biotechnology' mixes benefits with harms in one seamless package such that the knowledge outcomes of the Human Genome Project often collide in a supercharged vacuum of gung-ho determinist triumphacy. A collision that anthropologist Paul Rabinow (1999:23) derides as the 'hyperbolic discursive tidal wave of hope, fear and metadiscourse', and one that some clinically trained practitioners condemn with equal opprobrium as the dangers of a new age of medicalisation and rhetorical hype (Holtzman and Marteau 2000; see also Melzer and Zimmern 2002).

It is precisely such sensationalism strategies that I want to move away from so as to reorient debate through a different analytic trajectory. By traversing the conventionally discrete domains of ethics and science in post-Enlightenment European philosophy, this book unfolds as a cultural exploration of the way ethnographic analysis can be deployed as a critical tool to mediate the worlds of objective scientific 'fact' and subjective ethical 'value'. Part 1, 'Ethnography as linkage map', outlines some key themes and locates the nature of the ethnographic problem in terms of a culturally resonant 'linkage map'. Before I start to sketch in these points of linkage, let me account a little more explicitly for some of the ethnographer's own concerns. Social scientists may be trained to deride hype, but such critical detachment does not abstain me from participatory engagement, albeit more subtle and reflexive forms of involvement. Nobody after all can write as though they were *tabula rasa*.

I want to present three caveats along the way. The first is nothing more than an acknowledgement. It is to make the rather simple but critical point that a wide range of genetic tests with different degrees of predictability is currently under development. It is then seriously misleading to talk about predictive medicine as though it were a monolithic enterprise, since in so doing we underplay the significant difference between those high-risk families with a known hereditary illness (single-gene inherited diseases) and common complex diseases in the wider population (Mathew 2001). For the latter, the presence of gene variations or 'polymorphisms' may mean that genes represent fairly poor predictors of

disease. Take the example of workplace hazards and the case of an employer wishing to test job applicants with a predictive susceptibility test prior to the offer of an employment contract. Now a person's potential susceptibility to a chemical could be affected by hundreds of different genes that encode enzymes and molecules involved in many different metabolic pathways. Rather than any single genetic difference it may be the overall pattern of gene variation that will influence the possible onset of a health problem. Or genetic differences may be attributable to different metabolic transfer rates whose effects cannot be easily predicted. You may be able to break down toxic chemicals efficiently that prevent the development of a predispositional risk factor, whereas my body might not produce the right level of enzymes in the right amount, even though I feel and appear quite healthy. If we both keep our distance from the group of chemicals known as arylamines (associated with dyes, textiles and rubber manufacture), then theoretically our different metabolic rates as fast and slow 'acetylators' will be of negligible predictive value for the NAT2 gene variation linked with the increased susceptibility risk to bladder cancer. But the added caveat reveals the complex subtleties at work. The genetic variation in NAT2 that is thought to increase the risk of bladder cancer is also thought to reduce the risk of developing colon cancer. All in all, I may be more protected from colon disease than you! Any predictive genetic test result could therefore involve the misinterpretation of an individual's actual risk, thereby leading to social inequality through practices of genetic discrimination – my not getting the job appointment, for example.[4]

Second, as more tests for multi-factorial genetic disorders become available in the coming years in the form of so-called 'pre-dispositional' diagnostics, we need to think much more carefully about what is meant by the umbrella term 'preventive health'. This is especially so since preventive genetic medicine is couched so often in terms of helpful treatments and effective care, omitting to say that health prevention as a practice and ideology is also tied up closely with the political economy of health systems. If health policy administrators keep an interested eye on developments in the new life technologies, this is partly because it will be more cost effective to 'screen out' persons preconceptively or to treat certain conditions prophylactically, than it will be to subsidise the cost of long-term care for those with chronic symptoms. The National Institute for Clinical Excellence (NICE) produces for the National Health Service in England and Wales authoritative guidance on the clinical and cost effectiveness of healthcare interventions and on the treatment of clinical conditions. NICE has already produced clinical guidelines in familial breast cancer and undertaken appraisals for two medicinal products, trastuzumab (Herceptin) and imatinib (Glivec) that require the prior genetic analysis of tumour cells

before they are prescribed (Department of Health 2003:52). Sociological critiques of 'surveillance medicine' and 'genetic governmentality' have addressed already such important issues as medicines access within the larger cultural framework of social justice (see e.g. Armstrong 1995; Rose 1990; Kerr 2003). These critiques rightly stress the need to challenge and negotiate discursive claims that implicitly or explicitly seek to justify certain links between predictive medicine and new encroaching forms of bio-surveillance, for instance in the testing and selection of persons in employment, education and insurance contexts.

Third, predictive genetic testing also raises new questions and dilemmas for families. A common feature of genetic tests for diseases of Mendelian pattern of inheritance concerns the fact that an individual's test result usually has implications for other family members. Genetics affects more than ego; it is profoundly relational since one's genetic inheritance may bind the self to others. Genes do not just provide an individual with identity, they also 'relate persons to one another and give them an identity as 'relatives' (Strathern 1995:104). When knowledge about a person's anticipated health can become systematised as new predictive genetic information that is not only relevant to the testee but also to all his or her consanguineal kin, what exactly does it mean to talk of genetic futures? As the sociologists Alan Petersen and Robin Bunton observe, the new genetics as applied to public health will profoundly transform our concepts of self as embodied beings. 'It is in its potential to alter our view of ourselves and of our relationships with others that the new genetics has its most potent effects as a form of governance' (Petersen and Bunton 2002:30). What then happens to the link between culture and health when people start to anticipate social relations primarily as the time between diagnosis and an embodied prognosis, and when – perhaps most importantly of all – the remedy of a potential cure is still pending? Can everybody just continue to *laugh* like Elizabeth Gille in the face of changing conceptions of genetic heredity? And how are these new life technologies of prediction reconfiguring our understandings of moral obligation as modern familial forms of 'kinship ethics'?

In *The Voice of Prophecy*, anthropologist Edwin Ardener (1989) identified some of the pervasively elusive and paradoxical features inherent in both the idea and temporality of prophecy. Before they happen, prophetic situations may seem strange events without any comprehensible meaning or wider socio-cultural validation. In retrospect, however, the enduring effects of these situations often may seem so mundane and trivial that their instancing as new ideational associations seems barely recognisable as particular cultural forces *already* underway. Ardener's important theoretical point, developed as the 'prophetic condition', stressed that those claiming prophetic foresight do not in fact predict the future

in terms of the present. Rather, they foretell a present situation before it has been culturally validated and naturalised through linguistic representation. The prophetic condition, therefore, if it is to have any cultural salience, manifests itself as a new discursive language and puts into articulation the cultural contours of another social reality.

In examining various aspects of predictive medicine as a new discursive language, this book asks how contemporary developments in genetic science are shaping the contours of prophetic reality. To such ends, our enquiry probes extensively the emerging armoury of pre-symptomatic classification. Whereas diagnostic genetic testing is seen as appropriate for individuals already displaying particular symptoms, and more or less verifies or further refines diagnostic judgement about the presence of a particular disease, pre-symptomatic genetic testing is carried out on persons medically categorised and subsequently 'revealed' (or precluded from social labelling) as 'pre-symptomatic'.[5] As an extended commentary on the classificatory and ethical systems that support genetic governmentality through the creation of 'pre-symptomatic' value, *Narrating the New Predictive Genetics* pays close analytic and ethnographic attention to the lived condition that is the making of the pre-symptomatic person. We will hear the detailed testimonies from subjects who have undergone predictive genetic testing for a particular adult-onset monogenic (single-gene) condition. Others similarly share their real-life thoughts and anticipations enabling 'contexts to speak back' as the production of socially robust knowledge (Nowotny, Scott and Gibbons 2002). There are those who remain undecided as to whether they should get themselves tested pre-emptively 'ahead of illness' and spouses who find out they have married into an affected family once they have already had children. These are just some of the non-professional 'expert' voices detailing what gets spoken and what otherwise gets left unsaid in the co-evolving biocultures of prophetic genetics and society.

Hearing such voices from the ground is important for many reasons. For one thing, such articulations dovetail or cut across contemporary public policy debates over the uses of sensitive genetic information. Identifying a potential population of pre-symptomatic persons enables, of course, the collection of pre-emptively classifiable information about subjects' future health and well being. Such 'pre-emptive' capacities raise in turn many ethical and practical issues about data protection and the very notion of 'genetic privacy'. In Britain the ends to which genetic information can be put, particularly in the case of the establishment of human genetic databases and related issues of confidentiality and anonymisation, has been identified as an ethical and legal problem beyond the remit of scientific innovation and medical practice alone (House of Lords 2001). In its discussion document 'Whose Hands on Your Genes',

the Human Genetics Commission (2000) notes several reasons why personal genetic information may be seen as special and treated differently from other medical information.

(1) It is unique to each person (except for 'identical' twins).
(2) It is technically possible to obtain it from a very small bodily sample without a person's consent.
(3) It can be used to predict disorders a person may develop in the future and may tell other family relatives about disorders they may develop too.
(4) These predictions can be of interest to others such as insurance companies or employers.
(5) It has a potential commercial value to organisations introducing developments based on genetic information.

As we shall see, the question of whether genetic information needs to be protected in a different way to other personal medical information is clearly a public health concern of interest to everyone, and not just health advisors and practitioners. The claim of 'genetic exceptionalism' is made all the more explicit a social problem in the context of an encroaching 'consumer genetics' and the commercialisation of 'do-it-yourself' self-testing home kits for certain conditions or susceptibilities. As the technology of predictive genetic testing moves gradually beyond the specialised field and expertise of the medical genetics clinic, so the issue of the status of genetic information begs the increasingly pervasive cultural question: how does pre-emptive genetic knowledge make out of persons moral systems of foreknowledge?

Bodies into oracles

The entry of the 'anthropologist as diviner' in such prophetic contexts is never a straightforward or isolated act. S/he experiments first in the consultative exercise of anticipatory ethnography in order to foretell certain pre-emptive futures and in this sense comes to be directly implicated in the engagement of ethical process and deliberation. As we shall see, the event of foretelling takes place partly through the literal work of a narrative ethics that challenges sociobiological conceptions of an evolutionary ethics (see Chapter 2 'Sociobiology as a new modern synthesis?'). In the ethnographic chapters (Parts II–III) we witness this as the workings of a locally conceived 'kinship ethics' put into practice as a temporally inflected 'genealogical ethics'. But the narrative ethics of foretelling and the ongoing kinship work of disclosure happen also to entail asking related questions about the responsibilities of 'applied anthropology' and issues of research advocacy. How, for instance, can we ensure that the ability to perform

pre-symptomatic tests will not be transposed at some future moment into the normative imperative to have oneself genetically tested? If such conjecture seems far-fetched and if memories of past eugenicist abuse are thought sufficient a political check, then just listen to the plea for a 'psychocivilised society' advanced as recently as the late 1960s by Linus Pauling. A respected Nobel Prize winner on two occasions, once for chemistry and once for peace, Pauling was to advocate:

> there should be tattooed on the forehead of every young person a symbol showing possession of the sickle-cell gene or whatever other similar gene . . . It is my opinion that legislation along this line, compulsory testing for defective genes before marriage, and some form of public or semi-public display of this possession, should be adopted.
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> *(Quotation from Linus Pauling [1968:269] cited in Kay [1993:276])*

At the present time there are growing public concerns about the potential eugenic aspects of emergent genetic knowledge. Many are inclined to see certain analogies between current developments in the 'new genetics' and former state-sanctioned eugenic practices prevalent in parts of Europe and North America. Others disagree that any meaningful comparisons can be made between the old style coercive eugenics and the so-called 'new eugenics' (see e.g., Kerr and Shakespeare 2002; Petersen and Bunton 2002:35–66; Hubbard and Wald 1993: 23–38; Rifkin 1998:128–29; Proctor 1992). In the light of such claims it is worth bearing in mind that whilst developing his thesis on the 'birth of the clinic' in Western biomedicine, Michel Foucault would often speak of Georges Canguilhelm, his theoretical mentor, as a 'philosopher of error' (Foucault 1966: xix). Canguilhelm, for his part, had argued against a view of pathology as homologous with the intrinsic physiology of a specific biological (and cultural) organism. Whatever is classified as 'abnormal', he insisted, could only be evaluated in terms of relationships. 'Life is what is capable of error . . . [and] . . . the concept of error, like the concept of pathology, is polysemic' (Foucault *ibid*, paraphrasing Canguilhelm). Of course it is almost something of a truism to say today that new biotechnological applications have opened an arena for contests of power over what it means to be human, as well as how and who has the power to define what counts as 'normal'. As ever, hype and sensationalism galvanise public interest, in part, through certain media representations. And no less so amongst scientific communities keen to attract large research funding grants. Criminologists, psychologists, social welfare workers, family therapists and others may also see a direct application here to genetics behaviouralism debates (Nuffield Council on Bioethics 2002). But people do not become magically more or less 'normal' or 'human' *because* molecular biologists

have identified the corporeal location of particular genes, and can hope to understand better the partial implication of these biochemical structures in human disease aetiology and illness incidence. Nor can cultural organisms appear to 'disappear' any the more effectively simply because these same scientists can point to the similarity of deoxyribonucleic acid content between (say) a human, chimpanzee or banana. As social science critiques of 'genetic fetishism' and 'geneticisation' have stressed so well (e.g. Lippman 1993; Rose 1997; Rapp 1999; Finkler 2000), these scientific developments have to be translated to particular contexts and particular persons in order for their cultural and ethical salience to carry any kind of socially meaningful 'predictive' value. Nonetheless Pauling's comments and similar utterances cannot be overlooked. They serve as a wake-up call for the ease with which future scenarios can already be introduced into public consciousness in terms of what presently seem palatable 'get out' clauses (cf. Ardener's [1989] 'prophetic condition'; cf. Duster's [1990] 'backdoor'). Once genetic testing technology is routinised as mass screening programmes and broadly institutionalised as part of what in the late 1980s was already identified as 'the new diagnostics' (Nelkin and Tancredi 1989:3–19), how will an adult's future personal decision *not* to take a genetic (predisposition) test be respected as a legitimate and 'normal' choice?[6] How do we imagine to ourselves the need to ensure such 'choice' is not represented by medical elites and biotechnological venture capital as a moral failure of courage, or else reduced simply to the personal whim to 'remain ignorant' of important 'revelatory' (read: cost efficient) knowledge? As the UK's Human Genetics Commission (2000:19) notes in the context of contemporary debates about the 'right to know' and 'not to know' genetic information, to what extent should we – and can we – protect people from unwanted knowledge about their genetic status and personal future? While public and professional discussion has not so far included anthropological knowledge within its consultative range, our commentary asks what contemporary social anthropology might add to these pressing debates. What might anthropological approaches have to offer?

The organisation and symbolism of predictive cultures are by no means novel subjects of ethnographic enquiry for social anthropologists. Ethnographic and historical analyses of divination and prophecy have recorded the special mediatory powers of medicine men, high priests, spiritualists, elders and others to interpret and avert both past and future misfortune.[7] Whether the scale of affliction is perceived as relatively circumscribed to a few persons' neglectful relations with ancestors, or manifest as a more extensive form of group-level suffering, divinatory processes all follow particular set routines by which otherwise inaccessible, or 'hidden', information is obtained by culturally accredited

'experts'. Because divination has been conceptualised as a mystical technique allied to magical [read 'primitive'] medicines, anthropologists of the structural-functionalist persuasion fell readily into slotting the concept of divination into the intellectualist perspective of the relative rationality of a given culture and its peoples.[8] However, drawing upon existing ethnographic data, there are a number of *limited* parallels one may ascertain between previous anthropological analysis of divination in non-Western cultures and the scientific cultures of prediction of early twenty-first century biotechnology.

Evans-Pritchard's (1937) seminal anthropological investigation of links between oracles, magic and manipulation among the Azande locates the power of revelatory effect at the corporeal level of the human body. In Zande divinatory practice, ordeals are likened to trials by divination whereby an accused person's *body* becomes the determinant of the unknown. In activating a form of socially innovative transformation, oracles require the performance of an experiment to determine the unknown (for instance the administration of *benge* substance to fowls).[9] The divination, then, is supposed to create a sense of certainty as to why things have happened; to reveal the truth as a kind of divinatory authority (Whyte 1991:165). Writing on forms of power and manipulation in Sierra Leone, especially the dynamics of Temne divinatory knowledge, anthropologist Rosalind Shaw suggests that the 'divisions of oracular labour' involve a truth-constructing process that leads to a '*public reclassification of people and events*' (Shaw 1991:140, emphasis added). Like the 'decoding' practices of genomics that attempt to map the human genome by sequencing the formerly obscure and unknown DNA code (see Chapter 2), the temporal logics of divination combine the *techne* of revelation and concealment with that of manipulation and transformation (i.e. of divining tools, identities and bodies).

Note however this is not to say that genetics and divination *are* isomorphic practices, only that both deploy a set of practices as certain kinds of skill or *techne*. I am of course turning the anthropological tables somewhat and stretching the traditional meaning of the diviner's role as cultural innovator, at least as exemplified by certain area-specific ethnography. Diviners of course are ritual specialists whose interventions are usually made manifest as specific effects by way of a special mediating or intermediary object. The *yiteendi* for instance is a coin or small piece of cloth in the diviner's possession which, as the Yaka people of Zaire insist, must have been in physical contact already with the aggrieved person who is making a claim against a past affliction (Devisch 1991). As I am intimating however, it is also possible to see in the person of the social anthropologist a mediating relation and intermediary object that moves between the domains of 'science' and 'ethics'. In the particular British