Between Knowledge and Practice:

On Medical Professionals, Patients, and the Making of the Genetics of Cancer

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Abstract

In this paper, I examine the historical development of a clinical test for 'familial adenomatous polyposis', an inherited condition which often leads to cancer of the colon. By paying attention to continuities and changes, especially in the engagement between those medical professionals and patients involved in the development of this test, I reconsider the relationship between knowledge and practice, with an eye to Michel Foucault's and Paul Rabinow's competing notions of 'bio-power' and 'biosociality'. I conclude by offering some speculative suggestions for further avenues on inquiry into the constitution of the 'subject'.

Keywords

Bio-power, Biosociality, History, Eventalisation, Michel Foucault, Paul Rabinow

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Things fall apart; the centre cannot hold,

Mere anarchy is loosed upon the world

William Butler Yeats, ‘The Second Coming’, 1921

A recollection

I will start with a recollection. In 1995, I was beginning a new project on the history of medical research in Britain, focusing especially on genetics, 'old' and 'new'.[i] A small report in the Sunday Times caught my attention. Its gist is captured by the following few lines:

> British doctors will for the first time use a test to select cancer-free babies next month. The procedure raises the prospect of designer babies … Embryos of a woman with a high risk of passing on a form of bowel cancer will be screened and only healthy ones will be re-implanted. The same technique is likely to be used within two years to screen test tube embryos for a predisposition to inherited breast cancer.[ii]

The 'woman' in question suffered from a medical condition known as 'familial adenomatous polyposis'. It is a rare condition, but it has nonetheless been the subject of much medical investigation because it has often seemed to provide a 'model' for understanding the relationship between cancer and heredity that does not fall into any facile genetic reductionism. The salient characteristic, which makes the condition so interesting to medical professionals, is some people's inherited tendency to develop, in teenage years, innumerable polyps throughout their colorectal tract. Eventually, some of these polyps will become malignant and lead to cancer of the colon. The initiation of this complex process is now attributed to a fully sequenced mutation of the APC locus on chromosome 5q21.[iii] Significantly, the final, often deadly outcome of 'familial adenomatous polyposis' is preventable. Parts colon can be surgically removed as they become infested with the polyps, but in the case discussed in the Sunday Times this preventive intervention also meant that the woman was no longer able to bear children. Artificial insemination of the woman's ova and the screening of the resultant embryos for the 'FAP' mutation, however, promised the woman a bright future. She would once again be able to bring children into the world, children who would not fall to the cancer that had already killed her mother and two sisters. Yet, the report in the Sunday Times also raised the prospect that this noteworthy medical achievement was the first step to the production of 'designer babies'. This phrase encapsulates a common fear that genetic knowledge and its associated reproductive technologies signal a return to eugenics, a fear which until recently has inclined the Human Fertilisation and Embryology Authority to prohibit pre-implantation embryo screening anywhere in Britain.[iv]

From recollection to event

I am often struck by the way in which the evocations of a return to eugenics, the selective reproduction of human beings, now more 'medicalised' than was ever the case in the early twentieth century, often portray patients and their families as passive objects of 'professional' intervention.[v] On the one hand, if these interventions are evacuating the meaning of 'human subject', this is a fitting consummation of a widely rehearsed narrative of the historical development of modern medicine. According to this narrative, the patient has gradually, but inexorably ceased to be the formative agent he or she had once been. The patient has 'disappeared'.[vi] On the other hand, medical professionals seem today absolutely bewildered by the diversity of patients' responses to the genetic services they are being offered. In fact, around the time of the report in the Sunday Times, the Times Higher Education Supplement published a long interview with Theresa Marteau, the director of the Psychology and Genetics Research Group in Guy's and St. Thomas's Hospital. In this interview, Marteau discussed her efforts to better understand patients' diverse responses to pre-natal screening, efforts that paid particular attention to the developments around 'familial adenomatous polyposis'.[vii] As I began my project on the history of medical research in Britain, it seemed to me that such concern contradicted the argument that modern medicine has become a monological enterprise, in which medical professionals alone speak with any authority. This scepticism, however, can be called into question in at least two ways, both of which would transform the small report in the Sunday Times into a momentous 'event'.[viii]

Martin Richards has argued that patients' responses and their reasoning can only be as 'interesting' as Marteau seems to find them if they contradict a tacit, medically rational presupposition that a genetically defective embryo should be aborted.[ix] Furthermore, Marteau may point out that genetic considerations are only one class of the many involved in patients' decisions about reproduction, and that, therefore, all that medical professionals like herself should do is to enable these patients to make a more informed choice.[x] Yet, the presumed freedom of choice may be more apparent than real. It has certainly been facilitated by the ongoing reforms of the National Health Service, which aim to reposition patients as 'informed consumers' in a novel medical marketplace where economic rationality reigns supreme.[xi] Thus, Sir Walter Bodmer, a renowned geneticist, leading figure in the British effort to decode the human genome, and former director general of the Imperial Cancer Research Fund, has recently noted that patients' choices regarding genetic screening for 'familial adenomatous polyposis' are not made in a vacuum. They must instead be balanced against their cost to the increasingly insolvent National Health Service.[xii] Marteau's attentiveness to patients' responses to pre-natal screening for 'familial adenomatous polyposis' does not then invalidate the narrative of a return to eugenics, this time, conducive to logic of advanced consumer capitalism rather than the logic of the corporatist state.[xiii]

Alternatively, one might heed Michel Foucault's objections to such 'grand narratives', and argue that, in acting as 'informed consumers', the patients studied by Marteau are not the objects of 'professional', if not 'social', control evoked by Richards. They are instead constitutive figures of a new 'discourse', in which patients' genetic endowment is an integral part of how they understand themselves.[xiv] The increasing prominence of patients' groups in the evolution of research programmes into the genetic bases of disease certainly lends great weight to this perspective. What seems more compelling, however, is the way in which those patients who decline the offer of a genetic test, seem to do so without ever calling into question the legitimacy of what Evelyn Fox Keller calls 'gene talk'.[xv] These paradoxically affirming refusals bear witness to the new age of 'bio-power', an age dominated by the internalisation of disciplinary knowledge and regulatory practices focusing on human reproduction. If anything can then be said about disappearance, it is not the 'patient' who is disappearing, but the 'human subject' of the modern imagination.[xvi]

For all the differences between these two perspectives on the relationship between knowledge and power, however, Paul Rabinow has recently charged both of them with an inordinate attention to knowledge, which fails to recognise how profoundly the world is changing today. In French DNA, a genealogy of recent debates over the ownership of the information encoded in French patients' genome, Rabinow is entirely dismissive of the 'hermeneutics of suspicion', which motivates theories of 'professional' and 'social' control. Professionals, he argues, can no longer be viewed as 'knowledgeable', but should instead be viewed as 'experimenters' in a world where the once secure distinctions between the 'natural' and the 'political' are no longer tenable.[xvii] The difference between the two 'forms of life' becomes clearer in Rabinow's perceptive essay on 'Enlightenment and Artificiality'. Focusing on the 'anthropological triad — life, labor and language', Rabinow argues that the contemporary transformation of human existence is not predicated on transformations in the domain of 'language' or 'knowledge'. It is instead taking place in the domain of 'labor' or 'practice'.[xviii] In this domain, an increasingly unstable 'knowledge' is an effect rather than a cause of constant movement and reconfiguration across the once hallowed boundaries between the worlds of political, if not ethical, argument, on the one hand, and scientific and technological innovation, on the other hand. The challenge of the day is no longer to answer question about what is, nor is it to answer questions about what should be, but to act. This fundamental change may explain why disciplinary 'knowledge' no longer appears to enjoy its earlier authority. As Jonathan Freedland, a columnist for the Guardian has put it, we are today waving 'goodbye to the oracle', to the expert who once claimed to know what the future holds in store for us.[xix] Moreover, as Madeleine Bunting, another columnist for the Guardian, has noted, as a consequence of the growing scepticism about professional knowledge and the momentous transformation we expect from the decoding of the human genome, we are left with 'no moral compass' against which to set our bearings.[xx] In the context of such uncertainty, Rabinow advocates a new ethic of being. This ethic must be grounded in a 'will to experiment' that is much more open to the future and the heterogeneous than the insouciant 'will to knowledge' that greatly worried Foucault, in the first volume of The History of Sexuality, originally entitled La Volonté de Savoir.[xxi]

In this paper, I wish to reconstruct a history of 'familial adenomatous polyposis' in the light of Rabinow's critique of the relationship between 'knowledge' and 'practice'. My claims are two. Firstly, the novelty and radical difference of the discourse of 'biosociality', the label by which Rabinow differentiates his position from Foucault's, needs some revision. By attending to the very practices that produced the genetic explanation of cancer, on which the novel procedure described by the Sunday Times depended, it would seem that the evolution of this explanation has always been characterised by negotiations between patients and medical professionals.[xxii] This dialogical engagement calls into question the stability of 'knowledge' and the discourse of 'bio-power', thus lending still greater credibility to the more fissiparous and centrifugal discourse of 'biosociality'.[xxiii] My second claim is, however, that in his normative rendition of Gilles Deleuze' theorisation of life and social order, if not Bruno Latour's 'actor-network theory', Rabinow's account of the fate of 'knowledge' is at least inconsistent. For example, he suggests that the narrative of a return to eugenics that often characterises 'gene talk' is a fundamentally conservative rhetorical practice insofar as it forecloses the future, by revelling in 'suspicion', and thus depriving the world of hope for a world in which children will not die needlessly.[xxiv] Our first responsibility, he argues, is to those around us, embodied people whose life is finite, not to literally disembodied ideas of the 'good'. Yet, Rabinow himself is not the 'disinterested' witness he evokes when he describes his reflexive stance as,

> An experimental mode of inquiry … where one confronts a problem whose answer is not known in advance rather than already having answers and then seeking a problem. [xxv]

Not only is the thrust of Rabinow's argument normative, but it also relies on 'knowledge', specifically historical recollection, to emphasise the novelty of the coming age of 'bio-sociality' with the tired age of 'bio-power' that was. My argument then is that recollections of past dreams of a perfectly measured and adjusted society, or the memories that inform patients' choices about the genetic test for 'familial adenomatous polyposis', are inseparable dimensions of being orientated toward the future. In other words, 'practice', however disruptive and iconoclastic, is always located in a context of something fundamentally different, namely that 'knowledge' which helps us to steer, as we seek impossibly to bring the future into account. There can be no 'will to experiment' without a 'will to knowledge'.[xxvi] As Bernard Barataud, the charismatic leader of the Association Française Contre les Myopathies who plays a central role in the narrative of French DNA, once put it, 'without knowledge there is no hope'.[xxvii]

Conditions of possibility

For contingent reasons that need not be rehearsed here, as I began my new project on the history of medical research in Britain, I became interested in the Polyposis Registry, in St. Mark's Hospital, one of the leading hospitals for the treatment of diseases of the colorectal tract.[xxviii] The Registry occupied a couple of inconspicuous rooms, one of which was taken up by a dozen filing cabinets. These contained the medical records of innumerable patients, as well as these patients' family histories, some correspondence between medical professionals, patients and these patients' relatives, and a number of publications relating to the work of the Registry. A story began to unfold as I tried to weave these very different fragments together.[xxix]

In 1882, Harrison Cripps, a surgeon at St. Bartholomew's Hospital, claimed that 'polyposis intestini', a polypal infestation of the colon, was a 'familial' condition leading to cancer of the colon.[xxx] This claim, based on observations about two sisters who Cripps had been treating, was not examined any further for another forty years. Percy Lockhart-Mummery, a surgeon at St. Mark's Hospital, returned to it in the wake of contemporary experimental work supposedly demonstrating that cancer was a genetically determined disease.[xxxi] Focusing on the polyps and their frequent, but not determining association with cancer of the colon, Mummery argued that a hereditary predisposition did not explain what caused the manifestation of the cancer. He then began to build a more complex theory by using genealogical data, which he had been collecting and storing in St. Mark's Hospital. From 1932 onward, he argued that families suffering from 'polyposis intestini' shared a gene that specified an instability of the somatic genetic material, which then led to excessive cellular proliferation and increased chance of malignant mutations among these anomalous cells.[xxxii]

Significantly, the collection of the records on which Mummery built this explanation depended on a network of consultants who had passed through St. Mark's Hospital, as registrars, and had learned from Mummery a new mode of medical practice. As they exchanged their records, the encounter with persons afflicted by 'polyposis intestini' ceased to be the private relationship upon which members of the medical élite built their prestigious practices on Harley Street. These patients became instead exemplars of a shared, larger diseased group, whose investigation might reveal something about the mechanics of carcinogenesis more generally.[xxxiii] The social interconnection entailed in Mummery's method and explanation also meant that cancer became a 'social' disease. As genes were passed on from one generation to the next, and thus spread through society, so did cancer.[xxxiv] This radical transformation of cancer was reinforced by Mummery's more speculative discussions of the origins of cancer. It was a disease of a modern civilisation, whose failings could only be redressed by the adoption of 'controlled breeding'.[xxxv] I have argued elsewhere that Mummery's views on eugenics were too radical even for leading figures in the Eugenics Society.[xxxvi] Paradoxically, however, Mummery rarely linked these views and the treatment of cancer. In fact, he explicitly dismissed the contemporary proposals for the 'preventative' management of the disease articulated by William Cramer, a physiologist in the Imperial Cancer Research Fund who was interested in the relationship between 'intrinsic' and 'extrinsic' causes of cancer. Mummery wrote that,

> The chances of being able to prevent cancer on the lines suggested by Dr. Cramer is [sic] not a very hopeful one. There is, however, one point worth noting. Where it is known that certain individuals have possibly inherited a susceptibility to develop cancer in a certain organ, then if such individuals are carefully examined, as regards that organ, at regular intervals, there is an excellent chance of the lesion being detected during the early stage, when it is curable.[xxxvii]

Arguably, this was nothing but the result of Mummery's 'professional interest' in maintaining the priority of 'clinical' medicine over the discourse of 'social' medicine, but such an explanation raises questions about the reasons for Mummery's return to Cripps' claim in the first place.[xxxviii] To answer them, we must attend to Mummery's patients.

Mummery had become a renowned surgeon thanks to his private practice on Harley Street. His reputation as a specialist in the treatment of cancer of the colorectal tract depended on detecting it as early as possible. This was facilitated by his improvement of the electric sigmoidoscope, a rectal probe.[xxxix] The reach of the sigmoidoscope was, however, quite limited. Another way to inspect the colorectal tract for unusual growths was to predict their development long before they were betrayed by the symptoms of their cancerous transition, diarrhoea and anal bleeding. Studying patients' healthy relatives to detect patterns, and thus assess the risks of developing cancer might do this.[xl] Yet, the aristocratic patients on whose custom Mummery's renown rested would have been unwilling to reveal their family secrets about irregular bowel movements and anal discomfort to someone as inferior to them as a surgeon. This was especially so since these healthy relatives would then be asked to submit to a speculative and degrading sigmoidoscopy, which, as Sir Walter Bodmer acknowledges, still is an 'unpleasant procedure'.[xli] Establishing the genetic nature of cancer of the colon, which might then serve to justify on more polite, scientific grounds an otherwise rude inquiry about these patients' relatives, called for the surveillance of the relatives of the politically less difficult patients.[xlii] These were the poorer patients who were referred to St. Mark's Hospital, from humble cottage hospitals in London's East End. Unfortunately, however, these last patients were not always willing to repay the civic notables and patrons of St. Mark's Hospital, who sometimes interceded on the patients' behalf to win them admission into the Hospital, by co-operating with Mummery's inquiries. Similarly, in 1954, Peter Brasher, one of Mummery's colleagues at St. Mark's Hospital, recalled how twenty years earlier another colleague had sought repeatedly to study one particular patient's relatives, but

> co-operation … was never freely given, mainly because the father believed that all treatment was meddlesome. They would not communicate with their relatives or give their addresses. [xliii]

The contemporary correspondence between medical professionals and their patients, which was necessary to construct the family histories, does not reveal why the latter found the request so 'meddlesome'. We can imagine, however, that they, like Mummery's aristocratic patients, did not wish to submit their relatives to a speculative and degrading sigmoidoscopy. Given the thus limited data that Mummery could mobilise, his genetic explanation of cancer remained an unrealised technology of visualisation, rather than a platform for 'controlled breeding'. This also means that there is no necessary and immediate connection between genetics and eugenic ambitions.[xliv] Nevertheless, Mummery's practices established what Michel Foucault would have called the 'conditions of possibility' for such a connection.[xlv]

Disciplinary power and the amplification of dissonance

In 1956, the renowned geneticist J. B. S. Haldane argued, in a much publicised essay on 'the prospects of eugenics', that,

> It is the duty of a physician or surgeon to tell [anyone carrying the gene for 'polyposis coli'] that about half his or her children will at worst die of cancer, at best be condemned to a life of semi-invalidism ... [S]uch persons should be taught methods of birth control; perhaps they should be given the opportunity of voluntary sterilization. [xlvi]

The momentous conceptual transformation of the now re-named ‘polyposis coli’ into an exemplary genetic disorder that was also eugenically significant was facilitated by the reorganisation of medicine under the National Health Service. Those charged with this reorganisation questioned the future of St. Mark’s Hospital as an ‘independent special hospital’ because they did not view ‘proctology’, the science of the colorectal tract, as a legitimate medical specialisation. This prompted the creation of a financially independent Research Department, with Cuthbert Dukes as its first director, to reinforce the notion that St. Mark’s Hospital was nonetheless an important centre for medical research. At the same time, the National Health Service was committed, at least in principle, to ‘social’ medicine.[xlvii] While epidemiology is the most notable discipline associated with this form of medicine, genetics was also very important since its approach to understanding, if not treating, disease was fundamentally social.[xlviii] Dukes’ appointment was due largely to his alignment of polyposis, genetics, and ‘social’ medicine.

Percy Lockhart Mummery had brought Dukes onto the staff at St. Mark's Hospital in 1922, to take over a new 'pathological laboratory'. Although Dukes' professional qualifications in public health certainly marked him as much more open to 'social' medicine, Lockhart Mummery was more interested in his statistical expertise. The possession of such expertise led him, among other things, to entrust Dukes with the collection of the 'family histories' of patients suffering from 'polyposis intestini'. Importantly, much of the expertise in the collection and analysis of what were now understood as 'pedigrees', as opposed to 'family histories', rested with the Eugenics Society. Dukes eventually joined the Society, just as members of Medical Research Council's Committee on Human Genetics were seeking to shift eugenicists' attention to politically unproblematic clinical pathologies, hoping thereby to win greater acceptance of genetics within the medical profession.[xlix] Dukes, by then a respected clinical specialist, could help to advance this effort. His importance to geneticists was particularly evident in 1948, when he was asked to chair an international symposium jointly organised by the British Empire Cancer Campaign and the Genetical Society on 'the genetics of cancer'.[l] Dukes was then the perfect candidate for the appointment as the director of the Research Department.

Dukes, thanks to his newly acquired position and the important place it occupied in the institutional organisation of St. Mark's Hospital, could then begin to demand that his senior colleagues should collect and hand over to him blood samples from those patients who were afflicted by 'polyposis coli'. These senior colleagues' proprietary relationship with their patients continued to create problems, but Dukes succeeded nonetheless in forwarding increasing numbers of blood samples to the Galton Laboratory. Here, Lionel Penrose, one of the original members of the Medical Research Council's Committee on Human Genetics, was busy breaking the study of human genetics free from its association with eugenics by detaching interest in the evolution of human disease from questions of social policy.[li] Dukes also sought to expand the 'pedigrees' collected in St. Mark's Hospital by publicly calling on medical professionals around the world to inform him of any cases of 'polyposis coli' they might encounter, to ascertain whether they were in fact cases of 'familial polyposis coli'.[lii] In other words, the investigation of this condition was no longer the pet project of a surgeon at St. Mark's Hospital, intent on improving the efficacy of his surgical interventions, but was being relocated into the heart of the new and international field of human genetics.[liii]

This relocation was accompanied by a much greater openness toward prevention, a central tenet of 'social' medicine. Thus, in 1951, the first of an increasing number of more affluent patients to come within Dukes' purview expressed some concern about the reproductive implications of their condition, asking Dukes whether they should be sterilised to avoid bringing into the world similarly affected children. Dukes recommended that they should instead visit a 'good family planning clinic'.[liv] Others, such Tom Rowentree, a young surgical registrar at St. Mark's Hospital, were not at all averse to thinking about the more drastic course of action envisioned by this patient, and publicly endorsed by Haldane.[lv] Arguably, however, this no longer constituted 'eugenic' advice because it was not predicated on the social, if not racial, biases that once characterised such advice. Yet, the language Dukes used to describe how to collect family histories suggests otherwise. He wrote that,

In each family one individual is selected who is called the collaborator. This person is chosen with care. … The essential quality of the collaborator must be that he or she is 'tribal' in outlook, is the sort of person who knows nephews and nieces or aunts and uncles. Having chosen the collaborator, I make note each year in my diary of his or her birthday and write annually so that the birthday letter arrives on the right day. Before writing the letter I consult the family chart, making note of the members about whom information is most needed. Then after expressing the usual birthday greetings I inquire after little Alice or Sister Susie or Uncle Tom or whomever it may be, enclosing, of course, a stamped addressed envelope for reply. [lvi]

The connotations that the word 'collaborator' may have had in post-war Britain, especially when the patients often worried about 'informing' on their relatives, certainly were unfortunate. More importantly, however, the general tenor of these instructions was inflected by an 'anthropological' outlook, if not by an overtly racialised understanding of the lives of residents of the London East End.[lvii] Such inflection was still, if not even more, evident in 1977, when Richard Bussey, Dukes' long-serving assistant, wrote to a colleague that,

We have sent our beaters out after some polyposis children who have not been seen for a while or not at all. One of these patients has apparently been caught in your net.[lviii]

From a 'practical' perspective, social distinctions, grounded in the racialised differentiation that once shaped the language of eugenics, including British eugenics, continued to inflect the language of human genetics.[lix]

Strikingly, the families on which the construction and extension of the Dukes' pedigrees depended often resisted Dukes' entreaties for information, and the correspondence in the files of Polyposis Registry now provided much more insight into the unwillingness to co-operate. In 1949, for example, Dukes' journey to visit one patient's relative, a 'labourer' in Blackburn, were repeatedly frustrated, largely because this relative protested that they were quite healthy and had no intention of submitting to a sigmoidal inspection.[lx] Two years later, another patient was discouraged from collaborating because their sister, a nurse, warned them against becoming a 'guinia pig for surgions [sic]'.[lxi] More interestingly, these patients sometimes had very different ideas from Dukes and his colleagues about the reasons for their condition. Dukes' explanations that polyposis 'runs in the family' made no sense at all when 'Aunt Betty', who lived next door, died of cancer, even though her 'relatives' were now told that she was not 'really' part of the family. 'Black sheep' and illegitimate offspring, as well as different notions of kinship, often tripped Dukes and his colleagues, as they sought to link family histories and 'polyposis coli', and thus transform cancer into a genetically determined disease. Their difficulties sometimes led the patients to attribute the high incidence of cancer in their 'family' to a shared history of bad diet, rather than to shared 'genes'.[lxii] Such refractory voices could not be ignored, without risking the loss of precious 'informers'. Dukes and his colleagues then had to find a way of taking dietary factors into account and still sustain their preferred, genetic understanding. Thus, Hugh Lockhart Mummery, who had followed in his father's steps by also becoming a surgeon at St. Mark's Hospital, suggested that Dukes should respond to a patient's dietary explanation by arguing that,

> The dominant gene may be of low penetrance and that the hardships and intestinal upsets caused by his time as a prisoner of war in Japanese hands may have caused the appearance of overt disease.[lxiii]

The tension between, on the one hand, Dukes' and his colleagues' commitment to a genetic explanation, and the patients' environmental account, on the other hand, was being resolved by mobilising the concept of 'genetic penetrance', an index of the extent to which a genetically determined condition is clinically manifest.

In sum, the genetic explanation of 'polyposis coli' thrived under a National Health Service dedicated, at least in principle, to 'social' medicine and the expansion of cognate bio-medical disciplines such as genetics. Its network expanded well beyond the walls of St. Mark's Hospital. Following Michel Foucault, we might say that it became an integral part of a new and expansive 'disciplinary' apparatus. The National Health Service, however, was part of a reform of the British state that also encouraged once marginal people to oppose more brazenly the entreaties of their erstwhile social superiors. Gaining access to a specialist hospital such as St. Mark's Hospital, for one, was no longer a business of appealing to the charitable instincts of the Hospital's patrons, but a right. Patients expected to be treated on their own terms, not as 'guinia pig[s] [sic]', and sometimes they expressed their equality by articulating alternative explanations of disease, which had to be somehow confronted. Thus, as the genetic explanation of 'polyposis coli' circulated more widely, it also became more open to destabilisation.

Enter the laboratory

One respondent to Cuthbert Dukes' call for records of patients afflicted by 'polyposis coli' was Arthur Veale, a clinician in the New Plymouth Hospital, in New Plymouth, New Zealand. As Dukes and Veale exchanged notes about the possible genealogical connections between some of the families in their respective registers, Veale became very interested in Lionel Penrose's work on the linkage between 'polyposis coli' and genetically determined haematological markers.[lxiv] In 1960, he was appointed to a joint research post in St. Mark's Hospital and the Galton Laboratory.

Veale, however, was not interested in the demographic questions explored by Penrose, but in the light that the genetic explanation of 'polyposis coli' might shed on the process of carcinogenesis. Thus, in one of his first reports on the progress of his research in St. Mark's Hospital and the Galton Laboratory he argued that,

> If the onset of malignancy at a particular site is determined by the completion of a 'partial' mutation, the existence of such a mutation could be proved by demonstrating that it was linked with some other genetically determined factor. This would contribute more to a theory of carcinogenesis than any number of associations or family studies.[lxv]

Once Veale was convinced that 'familial polyposis coli' was an 'autosomal, dominant genetic disorder', the task was to understand why the newly re-named 'FAP' mutation did not completely determine the onset of cancer. What this new task involved was statistically complex 'linkage analyses' to establish connections with other genetically determined loci, whose physiological and biochemical manifestations were better understood than was the case for 'familial polyposis coli'. From now on, then, family records would no longer play a significant role in understanding the genetics of cancer. The British Empire Cancer Campaign, which had funded for the collection of familial data in St. Mark's Hospital for nearly forty years, ceased to do so. Richard Bussey was then appointed to transform the now financially independent Polyposis Registry into a reference collection for researchers well beyond the confines of St. Mark's Hospital. It eventually became a reference collection for the World Health Organization.

It would then seem that the future belonged to Veale and his intellectual successors, molecular geneticists. In the hospital ward, all that was needed to check for 'polyposis coli' was a blood test for increasingly refined biochemical signals. John Northover, a surgeon at St. Mark's Hospital, put the argument bluntly in 1984, when he introduced a new unit for the study of the molecular genetics of colorectal cancers. He stressed that,

> St. Mark's has played an important part in the evolution of the surgery of colorectal cancer, but surgery alone has reached its limits as a curative measure, and other methods of treatment must be explored. … New pathological techniques are being developed which reveal clinically important information on the biology of the disease, and these need to take their place in the assessment of patients at St. Mark's.[lxvi]

If the Polyposis Registry had any role in these novel developments, it was as a testing ground. In fact, the ready access it provided to a large population, whose genetic structure was now relatively well understood, meant that it was the ideal population for the clinical trial of the first chemical therapeutics that emerged from the research programme set in motion by Veale.[lxvii]

This downgrading of the Polyposis Registry from research tool to resource for therapeutic trials was, however, premature. The genealogical approach, seemingly exorcised by Veale's deft removal of the 'FAP' mutation into the laboratory, continued to haunt the latter.[lxviii] The intensification of research into the biochemical, and then molecular basis of cancer, which Veale effectively pioneered, was based on the assumption that 'familial polyposis coli' was a homogeneous, genetically determined condition. Yet, the very effort to explain the incomplete 'penetrance' of the 'FAP' mutation, by progressively excluding problematic cases, led to the proliferation of related, but nonetheless distinct, forms of polypal infestations of the colorectal tract. The uncertain genetic status of these excluded forms, however, was problematic for the grander significance of 'familial polyposis coli' as a 'model' for the genetic determination of cancer more generally. Veale, for example, worried that these disruptive, anomalous cases were due simply to the notoriously incomplete information about the families listed in the Polyposis Registry.[lxix] Such problems then called for a return to the Polyposis Registry. In other words, the genealogical constitution of the gene was not easily overcome, and the Polyposis Registry continued to be a crucially important, if now removed and invisible resource, which, coincidentally, began to expand more rapidly than ever before.[lxx]

With the contemporary increasing democratisation of British society, the once less than aristocratic became increasingly important political actors. One aspect of this newly acquired importance was the growing popular interest in 'family trees', which, like social and local history, became an occasion for the celebration of heritage among people who once did not have a history.[lxxi] The Polyposis Registry contributed to the development of this 'history from below' by becoming a centre for exchange of family histories between patients and medical professionals, and, through them, between patients across the world. One particular patient discovered to their great excitement previously unknown relatives who had emigrated to New Zealand. In thus willingly participating in the construction of the family records, for reasons quite different from those of the medical professionals in the Polyposis Registry, the patients learned the new notions of kinship articulated by these researchers, and quite a bit about the genetic determination of disease as well. They began to speak with some confidence about 'genes', although Kay Neale, the Registrar of the Polyposis Registry, noted that they often got their 'Mendelian ratios mixed up'.[lxxii]

We need to be careful, however, about assuming that these patients had finally been incorporated into an emerging discourse of 'bio-power'. On the one hand, the increasingly more accurate identification of patients who were affected by polypal infestations of the colorectal tract, but not 'familial adenomatous polyposis', meant that they could be ignored by the Polyposis Registry. They simply become as anonymous as any other patients in the wards of St. Mark's Hospital. One such patient complained about their relegation by reporting how they were told that,

> The special polyposis clinic is a research clinic and you are not a suitable case for this! … What surprises me is that in earlier years - patients with polyposis, were always told that if there was any worries etc. don't hesitate to get in touch and the staff would help etc. It seems times have changed. [lxxiii]

In other words, such patients were no longer political subjects, intimately involved in the evolution of the genetic explanation of 'familial adenomatous polyposis', but were becoming instead the passive objects of disciplinary knowledge evoked by theories of 'professional', if not 'social', control. On the other hand, one might note how this patient's anger stemmed from their exclusion from the medical world, which could then be understood as indicating how this patient's identity had become tied to the medical domain, without any professional interference. As such, this patient's protestations would support Michel Foucault's arguments about the constitution of the subject of 'bio-power'. In other words, the meaning of any statement is ambiguous, to say the least.

The ambiguities of a family history

In 1992, prospective parents who were, or had at one time been, listed in the Polyposis Registry received a letter to inform them that,

> There have been some exciting new advances in our understanding of the genetic basis of polyposis, and this can provide us with new methods of ... testing an unborn baby. [lxxiv]

This letter came from a new 'genetic counselling' clinic, which was established in response to the financial difficulties confronting St. Mark's Hospital in the wake of a renewed national effort to reorganise the provision of medical care.

The advent of the molecular markers presaged by Arthur Veale's investigations and eventually recommended by John Northover promised more a definite identification of those members of an affected family who did not carry the gene than could possibly be afforded by statistical calculus of Mendelian genetics. More importantly, for the increasingly prominent managers at St. Mark's Hospital, the molecular markers promised relief from the need to call in members of these families for periodic examinations, and thus very important financial savings. Of course, the ghost of eugenics haunted Shirley Hodgson, the clinical geneticist heading the new

'genetic counselling' clinic. Like many of her colleagues, she worried that the counsel they offered might be construed as normative, and thus open them to accusations of renewing eugenics.[lxxv] She and others involved in this new approach to the management of polyposis then drew much comfort from the support for screening among their patients. As Northover pointed out, these patients were,

> Far more in favour of early diagnosis and application of linkage data to family affairs than their medical attendants might have thought.[lxxvi]

Not everyone, however, has been able to disengage the test and the ethical, if not political questions it raises as easily as Hodgson or Northover. Some patients have assumed that a positive diagnosis entails necessarily the termination of the developing foetus. One prospective parent, for example, declined to be tested because they 'did not think that a termination of pregnancy would be justified'.[lxxvii] Religious beliefs may have underlain this response, but it may have also been due to reading their family history differently from medical professionals.[lxxviii] Rather than focusing, as the latter were wont to do, on the fate of any prospective children, many parents may have begun to focus instead on how they came to find themselves consulting these professionals. They may have begun to realise from their family histories, which they themselves helped to construct, but read into the past rather than the future, that, even if affected, their children could eventually be operated and live a relatively normal life, just like their father or mother. For them, testing may have then been a matter of preparing themselves to live with an invalid child. As Hodgson reported after meeting a prospective parent, some of these patients were not worried by any 'psychological burden … of having an affected child'.[lxxix] In other words, the genetic information the patients are increasingly receiving from the 'genetic counselling clinic' is being translated into a personally meaningful datum to manage the risks and inevitable complications of everyday life, and sometimes, but only sometimes, do they opt for abortion. Of course, as Sir Walter Bodmer has noted, these choices come at some cost to the increasingly insolvent National Health Service.

Time will tell if, and how, such considerations will affect the course of patients' decisions.[lxxx]

In the meantime, one might begin to say that, when Theresa Marteau argued that the patients she studied, including members of the families in the Polyposis Registry, misunderstood the nature of their condition, she herself misunderstood the wide gulf between her and them. Puzzled by their responses, she suggested that,

> Even though they have been attending clinics and know quite a bit about [the inherited nature of polyposis], they still conceptualise it as being a multi-factorial condition ... it is not that they are ignorant, it's just that people have a sense that a gene may be necessary but not sufficient - there are environmental triggers. Scientifically, I don't think it's a bad way of thinking about it. [lxxxi]

Her response, however generous toward patients' understanding of genetics, rested on the sociobiological assumptions attendant on the contemporary expansion of genetics outside the laboratory. Marteau began with the gene as the foundational unit of analysis and admitted that environmental factors might sometimes mitigate its effects, though not in the case of 'familial adenomatous polyposis'. For parents, however, belonging to a family carrying a 'problem' gene may only be one among many factors that will shape their children's life. It may be no more significant for the making of a good life than either these parents' religious values or the variety of services that might attenuate the suffering of these children. These services include the same surgical interventions in later life that put the parents in the position to weigh the relative merits of these different factors. From this perspective, 'familial adenomatous polyposis' is indeed a 'multi-factorial condition', though not in the disciplinary, biological sense Marteau intended, which posited the environment as a disturbing rather than constitutive factor. Thus, even among those who share a common vocabulary, that of genetics, the appropriate way of reading a 'family history' is far from fixed, and thus a 'gene' is not always a 'gene'.[lxxxii] Communities of knowledge, or at least linguistic communities, are not necessarily

communities of practice, thus opening room for the production of more knowledge and new practices. As William Butler Yeats once put it, in 'The Second Coming', 'things fall apart; the centre cannot hold, mere anarchy is loosed upon the world', though I would remove the adjective 'mere' and add that 'anarchy' is the norm, which then raises questions about the narrative I have been constructing.

Dealing with the incommensurable

The development of reproductive technologies such as those described in the report in the Sunday Times, with which this paper started, is often viewed as a step toward a fundamental reconfiguration of human life. Some fear this reconfiguration as a return to eugenics, this time, conducive to logic of advanced consumer capitalism rather than the logic of the corporatist state. Focusing on the history of the genetic explanation of cancer on which the pre-implantation embryo screening that motivated the report in the Sunday Times was based, I have argued, however, that the situation is far more complex.

Percy Lockhart Mummery, the surgeon at St. Mark's Hospital with whom I opened my narrative, does not appear in any of the official histories of 'adenomatous polyposis coli'. These start instead start with the work of Cuthbert Dukes, the first director of the Research Department at St. Mark's Hospital. Mummery's name does, however, appear in many of the files stored in the Polyposis Registry, a relatively invisible department within St. Mark's Hospital that has proved critically important to the development of the pre-implantation embryo screening at the centre of the report in the Sunday Times. I have argued that the recording practices that lie at the heart of the Registry's work set what Michel Foucault would have called 'the conditions of possibility' for the evolution of a eugenic understanding of 'familial adenomatous polyposis'.[lxxxiii] Initially, the primary purpose of these practices was to reveal the interior of the clinical body, so as to improve the effectiveness of Mummery's surgical interventions. What was required for the actualisation of the possibility of a eugenic understanding of 'familial adenomatous polyposis' was the establishment of the National Health Service, which shifted the balance of power between the disciplinary practices of

'clinical' and 'social' medicine.[lxxxiv] I have also argued, however, that patients have been intimately involved with these developments because the extension of the Registry's records required their acquiescence to sharing information about their otherwise healthy families. Such acquiescence could never be taken for granted, especially in the wake of the transformation of British politics that led to the establishment of the National Health Service. These patients sometimes simply refused to collaborate in the genealogical investigations advanced by the personnel in the Polyposis Registry because they viewed medical professionals' inquiries about their relatives' health as unjustifiably intrusive. Occasionally, these patients' opposition has also taken the form of an explanation of their condition that is diametrically opposed to that proposed by the medical professionals. Most recently, however, these patients have argued instead that the genetic explanation of 'familial adenomatous polyposis' only provides a partial answer to their specific situations. The meaning of a 'family history' is not univocal. Today it is instead weighed against personal considerations and the recollection of alternatives to the termination of a pregnancy, such as the surgery in later life that put the patients in the position to weigh the options. Maintaining the alignment of medical professionals' and patients' understandings of their condition has then always been a business of constantly reformulating the genetic explanation, from the articulation of the concept of 'genetic penetrance' to a more sociobiological approach, in which the boundaries between genetics and sociology have become blurred.[lxxxv] This conclusion should perhaps have been far from surprising since the science of genetics, 'new' and 'old', has always rested on the blurring of boundaries between the 'natural' and the 'political' because 'genes' are about 'networks of kinship'.[lxxxvi] I want to draw, however, some further, perhaps more debatable, conclusions. Knowledge never is commensurate with empirical practice.

Contingency is one of the features of the narrative I have constructed around the report in the Sunday Times. The emergence of medical professionals' current understanding of 'familial adenomatous polyposis' was the far from inevitable. The reason is that medical professionals do not encounter 'patients' in the species existence imagined by modern medical discourse, but as individuated beings, 'Mr. X or Mrs. Y or Ms. Z', located in particular places with

particular memories. This evokes what Michel De Certeau would call 'tactical' responses.[lxxxvii] By their inevitably multiplicity and heterogeneity, these responses can easily destabilise medical professionals' claims to knowledge, to a knowledge that transcends the particularities of 'Mr. X or Mrs. Y or Ms. Z'. This, in turn, can evoke, and has evoked, a reformulation of such knowledge, which entails the incorporation of new considerations to enrol the dissonant voices of 'Mr. X or Mrs. Y or Ms. Z'. Admittedly, the disruptive 'recollections' that impel this dynamic are mediated, if not constituted, by the very genealogical records that were central to the constitution of 'familial adenomatous polyposis'. Of course, the same goes for this paper, rooted as it is in the very same records. Yet, this attention to practices and contingency does not explain why some patients read their pedigrees backward, into the past, rather than forward, into the future. Similarly, for all the contingencies that have interrupted the development of the professional discourse of genetics, the interruption has never halted it, perhaps because the eugenic dream never disappeared. Sometimes it was a haunting presence, from which Shirley Hodgson and John Northover sought to distance themselves, and sometimes this presence was made more concrete, for example when Sir Walter Bodmer hinted at the need for 'efficient health care'.[lxxxviii] In other words, there has always been an interplay between the world of immanence, to which the word practice speaks, and something excessive, something that is not of the 'here and now'.[lxxxix]

This brings me back to the relationship between 'knowledge' and 'practice'. While trying to clarify what he meant by 'discourse', Foucault characterised it as a 'space of dispersion', the historically contingent spatial distribution of knowledges and practices that establishes a particular subjectivity.[xc] In his earliest works, such as Madness and Civilization, the relationship between 'knowledge' and 'practice' was a tense one. They were incommensurable, but related entities, which thus opened the possibility for historical transformation.[xci] This tension, however, also opened room for powerful critiques of Foucault's work. The most incisive of these was perhaps Jacques Derrida's questioning about Foucault's ability to stand outside history and thus provide a historical account of the transformations with which he was concerned. This relied on an implicit, and to Derrida,

paradoxical, appeal to the very kind of historical meta-narratives Foucault sought to reject.[xcii] The critique certainly drove Foucault to establish an increasingly tighter relationship between 'knowledge' and 'practice', most notably in Discipline and Punish.[xciii] As Gary Gutting has noted, Foucault produced thereby a monolithic discourse, in which no 'practice' was outside the discursive 'power/knowledge' complex.[xciv] It was then reasonable to just collapse the differences between Foucault and Derrida, and argue that change testified to a semiotic space simultaneously unifying and disintegrating.[xcv] Being dissatisfied with the emphasis on 'language', Paul Rabinow takes up Foucault's own, increasing frustrations with the 'relentless theorization of writing', and proposes instead to hypostasise 'practice' rather than 'knowledge' as the locus of perpetual integration and disintegration.[xcvi] We live today in a world of 'doers' rather than 'knowers'. I am not sure what to make of these arresting reformulations, both of which certainly evoke change, but no temporality. Since nothing is ever stable, in anymore than the most anodyne manner, anything historically significant literally vanishes into meaninglessness.[xcvii] Ironically, even the concept of a past age when 'knowledge' was hegemonic, which supposedly differentiates the age of 'biosociality' from that of 'bio-power' and lends the former its disruptive power, vanishes. There can be no 'event', to divide the past from the future. In fact, there can be no future toward which the 'will to experiment' is supposedly orientated.[xcviii] Foucault himself was tacitly unwilling to accept such evacuation of 'discourse' with his conceptually problematic, but nonetheless powerful appeal to 'bodies and pleasures' as the veritable grounds of politics, if not history.[xcix] As Judith Butler has noted perceptively, this allowed Foucault to think about the future of humanity.[c]

I then want to resist the closure around either 'knowledge' or 'practice'. I want to preserve what Jacques Rancière calls 'incommensurability', an irreducible, structuring irruption that initiates, and indeed is the very precondition of, political engagement and historical transformation.[ci] More specifically, the evolution of 'polyposis intestini' into the "FAP' mutation of the APC locus on chromosome 5q21' was built upon a founding violence. This was the bestowal of families from the London East End with membership of a new community, the universal community of the genetically endowed, although the difference that

gave them a voice in this community was one to be erased. That is, the discourse of genetics endowed, and endows, the families in the Polyposis Registry with nothing but a negative quality: their 'problem' genes should be eliminated, if not re-engineered into 'unproblematic' ones. Like the demos of the classical polis, in which Rancière grounds his analysis, the families in the Polyposis Registry can then only bring 'contention' into this community. All they enjoy is the power to say 'no'.[cii] The situation is undoubtedly productive. 'Contention' is the engine of the transformation of 'polyposis intestini' into the "FAP' mutation of the APC locus on chromosome 5q21', a cause for celebration among the aristoï, the virtuous of the classical polis, who seek to bring about the well-ordered, and, as Bodmer puts it, 'efficient' community. Yet, this transformation also threatens the dissolution of politics. The families in the Polyposis Registry, like the Association Française Contre les Myopathies considered by Rabinow in French DNA, are beginning to constitute themselves as an 'interest' group, around their knowledge of a shared 'genetic' identity.[ciii] Something very precious could be lost, and not just the functionally productive agonism that results from incommensurability. Tom Shakespeare would appear to focus on exactly this point when he concludes his analysis of the threats presented by the medical applications of the 'new' genetics by turning to Derrida and writing:

> Earlier versions of eugenics did not have a disability movement to deal with: it seems to me, despite the difficulties, we could adopt a Derridean slogan: Vive La Difference [sic]![civ]

As Shakespeare notes, we need those endowed with 'problem' genes, as such. They act as a reminder of the contingency and violence of any discursive formation. They act as a reminder that productivity rests on violence. Yet, as Shakespeare fails to note, as he elides the difference between 'difference' and 'differánce', differentiation is also about a world to come, a world in which difference will be no longer.[cv] The presence those endowed with 'problem' genes then sustains a dialogue more significant than an engagement unable to effect anything but the further extension of discourse or the actor-network. It returns politics to its proper

place because it speaks to the 'knowledge' that the world might be otherwise than it is. In sum, there can be no 'will to experiment' without a 'will to knowledge'.

Finally, this reminder of the 'to come' that is implicit in any differentiation might provide the grounds for a renewed defence of 'interest theory', insofar as being 'interested' is then more than a sociological phenomenon. It is an ontological necessity of being. Equally importantly, however, it also seems to me as the place from which to return 'actor-network theory' to its initial and compelling emphasis on movement and fluidity.[cvi] To be, is to be caught irremediably between continuity and change, or even between the 'word' and the 'act', the two terms that lie behind the differentiation between 'knowledge' and 'practice'.

In the beginning was the Word

John, 1.1

In the beginning God made the heaven and the earth

Genesis, 1.1

Arguably, 'time' is the problem that lies at the heart of these competing notions of being, but that is for another paper, yet to be written.[cvii]

Notes

I wish to thank Kay Neale for granting me access to the records of the Polyposis Registry in St. Mark's Hospital, and for enabling me to interview members of the families included in the register. The latter, like the patients recorded by the register, will remain anonymous. Sometimes the effort to preserve their anonymity has resulted in the infelicitous use of 'they' in the place of 'he' or 'she', but I think this is more respectful, and yet more personable than 's/he'. I am very thankful to these anonymous voices. The argument of the paper would have not been possible, however, if it had not been for Claudia Castañeda, Simon Carroll, Michael Dillon, Paul Fletcher, Tim Hickman, Adrian MacKenzie, Kirsten McAllister, Maureen McNeil, Tiago Moreira, Torbjörn Wandel and Teresa Young. Over the years, their collective criticism of my ways of thinking about knowledge and practice has been invaluable. Any remaining faults are my own. Lastly, many thanks also go to David Edge and three anonymous referees for the help I have received from them in re-shaping this last draft of 'Between Knowledge and Practice'.

[i.] As a number of recent reviews of the medical implications of the 'new' genetics suggest, the distinction between 'old' and 'new' genetics is a matter of some disagreement. See Sarah Cunningham-Burley and Mary Boulton, 'The Social Context of the New Genetics', in Gary L. Albrecht et al. (eds.), Handbook of Social Studies in Health and Medicine (London: Sage, 1999), 173-87; and Jon Turney and Brian Balmer, 'The Genetic Body', in Roger Cooter and John Pickstone (eds.), Medicine in the 20th Century (Amsterdam: Harwood Academic Press, 2000), 399-415. The project I began seven years ago, aimed to examine the continuities and changes from the perspective of the clinic. Its results are discussed in greater detail in my book, Plants, Patients and the Historian: (Re)membering in the Age of Genetic Engineering (Manchester: Manchester University Press, forthcoming).

[ii.] Lois Rogers, 'Doctors to Create Cancer-Free Babies', Sunday Times, (5 November 1995), 24.

[iii.] For an introduction to current bio-medical understanding of 'familial adenomatous polyposis', see the electronic summary reviews maintained by the National Cancer Institute. On the increasingly problematic nature of 'model' diseases such as 'familial adenomatous polyposis' for the more general understanding of the genetic bases of disease, see Neil J. Risch, 'Searching for Genetic Determinants in the New Millennium', Nature, 405 6788 (2000): 847-56.

[iv.] See Sarah Boseley, 'Fertility Authority Faces 'Designer Child' Decision', Guardian, (2 October 2001), 11. For a review of this and the many other public issues surrounding the genetic explanation of disease, see the recent collection of essays 'Sociological Perspectives on the New Genetics', which was edited by Peter Conrad and Jonathan Gabe, and published in Sociology of Health & Illness, 215 (1999): 505-706.

[v.] For a seminal discussion of the semantic problems raised by the use of the term 'eugenics' to understand the medical applications of the 'new' genetics, see Diane Paul, 'Eugenic Anxieties, Social Realities, and Political Choices', Social Research, 59 3 (1992): 663-83.

[vi.] For an introduction to the literature on the 'disappearance' of the patient, see Roy S. Porter, 'Introduction', in Porter (ed.), Patients and Practitioners: Lay Perceptions of Medicine in Pre-Industrial Society (Cambridge: Cambridge University Press, 1985), 1-22.

[vii.] Gail Vines, 'Star of the Big Screen', Times Higher Education Supplement, (21 May 1996), 14. See also H. Drake, M. Reid and T. Marteau, 'Attitudes Towards Termination for Foetal Abnormality: Comparisons in Three European Countries', Clinical Genetics, 49 3 (1996): 134-40; and S. Whitelaw, J. M. Northover and S. V. Hodgson, 'Attitudes to Predictive DNA

Testing in Familial Adenomatous Polyposis', Journal of Medical Genetics, 33 7 (1996): 540-43.

[viii.] On the construction of the 'event', see Michel Foucault, 'Questions of Method [1977]', in Graham Burchell, Colin Gordon and Peter Miller (eds.), The Foucault Effect: Studies in Governmentality (Chicago: University of Chicago Press, 1991), 73-86, esp. 76-78.

[ix.] Martin Richards, personal communication, 11 November 1995. See also Richards, 'The New Genetics: Some Issues for Social Scientists', Sociology of Health and Illness, 15 5 (1993): 567-87.

[x.] See Theresa Marteau and Elizabeth Anionwu, 'Evaluating Carrier Testing: Objectives and Outcomes', in Marteau and Martin Richards (eds.), The Troubled Helix: Social and Psychological Implications of the New Human Genetics [1996] (Cambridge: Cambridge University Press, 1999), 123-39. For another incisive review of the issues raised by genetic medicine, see Anne Kerr's review of The Troubled Helix, in Kerr, 'Double Trouble: Social Analyses of the New Human Genetics', Science as Culture, 8 1 (1999): 97-103.

[xi.] See Richard Klein, The New Politics of the National Health Service (London: Longman, 1995), as well as David M. Cromwell et al., 'Cost Analysis of Alternative Approaches to Colorectal Screening in Familial Adenomatous Polyposis', Gastroenterology, 114 5 (1998): 893-901 and Bharati Bapat et al., 'Cost Comparison of Predictive Genetic Testing Versus Conventional Clinical Screening for Familial Adenomatous Polyposis', Gut, 44 5 (1999): 698-703. Significantly, the last two studies were produced in the United States, where the provision of health care is predicated on financial considerations far more explicitly than is yet the case in Britain.

[xii.] See James Meek, 'Gene Test Plea to Cut Cancer of Bowel Risk', Guardian, (27 June 2001), 5. On Sir Walter Bodmer's contributions to research into the genetic bases of 'familial adenomatous polyposis', see Bodmer, 'Familial Adenomatous Polyposis (FAP) and its Gene, APC', Cytogenetics and Cell Genetics, 86 2 (1999): 99-104.

[xiii.] For a recent and very provocative discussion of the renewal of eugenics, see Paul Virilio, The Information Bomb (London: Verso, 2000). Admittedly, other authors have advanced the argument that the medical applications of the 'new' genetics mark a return to eugenics long before Virilio, and they have done so in much greater detail than Virilio; see, for example, Troy Duster, Backdoor to Eugenics (London: Routledge, 1990). Virilio, however, integrates the argument into a much more widely ranging critique of the relationship between technology and the evolution of advanced consumer capitalism. For an introduction to Virilio's work, see John Armitage (ed.), Paul Virilio: From Modernism to Hypermodernism and Beyond (London: Sage, 2000).

[xiv.] See Michel Foucault, History of Sexuality: An Introduction [1976] (London: Penguin, 1990).

[xv.] In The Century of the Gene, Evelyn Fox Keller uses the phrase 'gene talk' to capture the proliferation within the community of biologist of a discourse centring on the 'gene', notwithstanding the increasingly problematic epistemological status of the 'gene'. See The Century of the Gene (Cambridge, Mass.: Harvard University Press, 2000). Dorothy Nelkin and Susan Lindee place this 'fetishisation' of the 'gene' in a much wider cultural context, which may help to explain contrary patients' silence. See The DNA Mystique: The Gene as Cultural Icon (New York: Freeman, 1995). The uncanny connivance of both champions and critics of the medical applications the 'new' genetics in 'gene talk' is drawn out very usefully in Tom Shakespeare's, "Losing the Plot"? Medical and Activist Discourses of Contemporary Genetics and Disability', Sociology of Health & Illness, 21 5 (1999): 669-88.

[xvi.] For a more sustained discussion of the differences between theories of 'discourse' and 'social control' with respect to issues of governance, see Mitchell Dean, Critical and Effective Histories: Foucault's Methods and Historical Sociology (London: Routledge, 1994), 141-73. Maintaining the differences between these theories becomes more difficult, however, when Michel Foucault admits to an important role for the dynamics of capitalism; see, for example, Foucault, 'The Birth of Social Medicine [1977]', in James Faubion, Michel Foucault: Essential Works of Foucault, 1954-1984 (London: Penguin, 1998-2000), Vol. 3, 134-56.

[xvii.] Paul Rabinow, French DNA: Trouble in Purgatory (Chicago: University of Chicago Press, 1999).

[xviii.] Paul Rabinow, 'Artificiality and Enlightenment: From Sociobiology to Biosociality', in Rabinow Essays on the Anthropology of Reason (Princeton: Princeton University Press, 1996), 91-111, on 92.

[xix.] Jonathan Freedland, 'Goodbye to the Oracle', Guardian, (9 June 1999), 19.

[xx.] Madeleine Bunting, 'Diving into the Unknown', Guardian, (12 June 2000), 17.

[xxi.] Rabinow, French DNA, 167-82.

[xxii.] From this perspective, the thrust of my argument is closer to Bruno Latour than Paul Rabinow, at least insofar as I am arguing that the constitution of knowledge has always been a matter of practical negotiation between heterogeneous parties. See Rabinow, 'Epochs, Presents, Events', in Margaret Lock, Allan Young and Alberto Cambrosio (eds.), Living and Working with the New Medical Technologies (Cambridge: Cambridge University Press, 2000), 31-46; and Latour, We Have Never Been Modern (Brighton: Harvester Wheatsheaf, 1990).

[xxiii.] Arguably, a further limitation of Paul Rabinow's argument is the partial way in which he constitutes his network of agents, so that 'muscular dystrophy', the disease on which he focuses his attention in French DNA, figures as an 'all or nothing' condition. Yet, many victims of the disease survive into advanced age, and some of them have actively campaigned

for the improvement of palliative care and other facilities that make their life easier, rather than for research to treat or even prevent the disease by selective reproduction. Such groups do not appear anywhere in Rabinow's narrative. It may be the case that such actors do not exist in the French case, although Vololona Rabeharisoa and Michel Callon's Le Pouvoir des Malades leaves room for doubt. Rabeharisoa and Callon argue that the notion that 'muscular dystrophy' should be addressed by support for genetic research was the outcome of protracted negotiations between diverse parties over the meaning of 'muscular dystrophy'. Significantly, these negotiations involved the reorganisation of diverse voluntary bodies, each characterised by very different orientations toward the world of biomedical research. See Le Pouvoir des Malades: L' Association Française Contre les Myopathies & la Recherche (Paris: Ecole des Mines de Paris, 1999), 11-12. While none of these groups would seem to have been interested in the promotion of better facilities for the disabled, such interest is certainly important elsewhere and in situations that often are just as dramatic as falling victim to 'muscular dystrophy'. In this paper, however, I take it for granted that any form of 'eventalization', the drawing of intersecting lines of causation that constitute the 'event', is always partial. In fact, while trying to provide a fuller understanding of the events reported by the Sunday Times, I will not attend to the obviously important issues raised by the development of in vitro fertilisation and embryo implantation. For a discussion of such developments, see Sarah Franklin, Embodied Progress: A Cultural Account of Assisted Conception (London: Routledge, 1997). I will instead seek to engage with Rabinow's argument about the significance of 'practice' on his own terms, however biased toward a constructive engagement between patients and medical professionals.

[xxiv.] See Rabinow, French DNA, 51-53 and 179. For an example of the intellectual proximity between Paul Rabinow, on the one hand, and Gilles Deleuze and Bruno Latour, on the other hand, see Rabinow, 'Epochs, Presents, Events' and 'Artificiality and Enlightenment'. Admittedly, Rabinow attempts to draw some very sharp distinctions between himself and Latour, and yet his normative conclusions in 'Epochs, Presents, Events', as well as in French DNA, do not seem incompatible with any that might be drawn from 'actor-network theory'. If there is a difference, it is that Latour is willing to draw general conclusions about ontological categories from studies of particular networks, while Rabinow wishes to avoid any such generalisation and accompanying shift from epistemology to ontology. Whether Rabinow's stance is in fact sustainable is open to question; at the very least, it begs questions about the purposes of writing books such as French DNA. For Latour's own efforts to transform 'actor-network theory' into a normative system, see Politiques de la Nature: Comment Faire Entrer les Sciences en Démocratie (Paris: La Découverte, 1999).

[xxv.] See Rabinow, French DNA, 174.

[xxvi.] For a recent effort to integrate recollections of the past within the conceptual framework of ethonomethodology, if not 'actor-network theory', see Tiago Moreira, 'Translation, Difference and Ontological Fluidity: Cerebral Angiography and Neurosurgical Practice (1926-45)', Social Studies of Science, 30 3 (2000): 421-46. See also Michael Lynch, 'Archives in Formation: Privileged Spaces, Popular Archives and Paper Trails', History of the Human Sciences, 12 2 (1999): 65-87. My approach will differ from Moreira's and Lynch's efforts insofar as I will focus on aporetic moments rather than active constructions of the past, apart, perhaps, from my own active construction. On this understanding, my approach is closer to Michel De Certeau's, when the latter discusses practices of reading. See The Practice of Everyday Life (Berkeley: University of California Press, 1984), 45-49 and 165-76.

[xxvii.] Bernard Barataud, quoted in Rabinow, French DNA, 40.

[xxviii.] For a history of St. Mark's Hospital, see Lindsay Grenshaw, St. Mark's Hospital, London: A Social History of a Specialist Hospital (London: King Edward's Hospital Fund, 1985).

[xxix.] One of the disadvantages of being a historian, interested in lost lives, as opposed to an ethnographer who observes the interactions of living people and is immersed in the same material culture as his or her actors, is that the record is extremely fragmentary, often for very important political reasons. On the other hand, the poverty of historians' archival records can force upon them greater attentiveness to interpretative practices and their problems. These practices and problems are discussed in a series of essays, which Irving Velody collected and edited for a special issue of History of the Human Sciences; see Velody, ' The Archive and the Human Sciences: Notes Toward a Theory of the Archive', History of the Human Sciences, 11 4 (1998): 1-16.

[xxx.] Harrison Cripps, 'Two Cases of Disseminated Polypus of the Rectum', Transactions of the Pathological Society, 33 (1882): 165.

[xxxi.] John Percy Lockhart-Mummery, 'Cancer and Heredity', Lancet, 1925, Vol. 1: 427-29. For contemporary scepticism about the genetic explanation of cancer, see 'Genetics and Cancer', Lancet, 1927, Vol. 2: 925-26; and Lancet, 1928, Vol. 2: 1137-38.

[xxxii.] John Percy Lockhart-Mummery, 'The Origin of Tumours', British Medical Journal, 1932, Vol. 1: 618-20. See also The Origin of Cancer (London: Churchill, 1934).

[xxxiii.] For a more detailed discussion of how practices of medical recording, such as the collection of the family histories discussed in this paper, actively reconfigure both patients and medical professionals, see Marc Berg, 'Practices of Reading and Writing: The Constitutive Role of the Patient Record in Medical Work', Sociology of Health and Illness, 18 4 (1996):

499-524.

[xxxiv.] As Roberta Bivins has noted informally, while cancer never became 'notifiable' like the infectious diseases that introduced the notion of 'social disease', there was much discussion in the early part of this century on what should be the proper attitude of public health authorities toward the disease. The discussion eventually resulted in the Cancer Act, which first established a national policy to combat the disease, and thus established cancer as a socially significant, but not infectious disease. I am grateful to Roberta for her help in clarifying this point. For a discussion of the transition from 'clinical' to 'social' medicine, see David Armstrong, Political Anatomy of the Body: Medical Knowledge in Britain in the Twentieth Century (Cambridge: Cambridge University Press, 1983).

[xxxv.] Lockhart Mummery, Origin of Cancer, 135.

[xxxvi.] Paolo Palladino, 'Icarus' Flight: On the Dialogue between the Historian and the Historical Actor', Rethinking History, 4 1 (2000): 21-36.

[xxxvii.] John Percy Lockhart-Mummery, 'Prevention of cancer', Lancet (1934), Vol. 1: 155.

[xxxviii.] For a discussion of Percy Lockhart Mummery and his contentious place in the institutional organisation of British medical research during the first decades of the twentieth century, and the problems this role presents for an account of the fraught relationship between 'clinicians' and 'medical researchers' in terms of 'professional interests', see Paolo Palladino, 'On Writing the Histor(ies) of Modern Medicine', Rethinking History 3 3 (1999): 271-88.

[xxxix.] John Percy Lockhart-Mummery, 'The Diagnosis of Tumours in the Upper Rectum and Sigmoid Flexure by Means of the Electric Sigmoidoscope', Lancet, 1904, Vol. 1: 1781-82.

[xl.] For a discussion of medical technologies of visualisation, see Lisa Cartwright, Screening the Body: Tracing Medicine's Visual Culture (Minneapolis: University of Minnesota Press, 1995). On the collection of records as a mode of visualisation, which, however, is not explored in Screening the Body, see Svetlana Alpers, 'The Museum as a Way of Seeing', in Ivan Karp and Stephen D. Lavine (eds.), Exhibiting Cultures: The Poetics and Politics of Museum Display (Washington: Smithsonian Institution Press, 1991), 25-32.

[xli.] Meek, 'Gene Test Plea to Cut Cancer of Bowel Risk'.

[xlii.] On the role of science in mediating the polite relationship between medical practitioners and their aristocratic patients, see S. E. D. Shortt, 'Physicians, Science, and Status: Issues in the Professionalization of Anglo-American Medicine in the Nineteenth Century', Medical History, 27 1 (1983): 51-68.

[xliii.] Peter H. Brasher, 'Clinical and Social Problems Associated with Familial Intestinal Polyposis', Archives of Surgery, 69

(1954): 785-96, on 789.

[xliv.] On the marginal status of 'polyposis intestini' in contemporary eugenic discourse, see Alfred Piney, 'Hereditary Neoplastic Diseases', in Carlos Blacker (ed.), The Chances of Morbid Inheritance (London: Lewis, 1933), 373-77.

[xlv.] Michel Foucault, The Order of Things: An Archaeology of the Human Sciences [1966] (New York: Vintage, 1994), xxii.

[xlvi.] J. B. S. Haldane, 'The Prospects of Eugenics', in M. L. Johnson, Michael Abercrombie, and Gordon E. Fogg (eds.), New Biology (London: Penguin, 1956), Vol. 22, 7-23, on 9-10.

[xlvii.] The role of 'social medicine' in the evolution of the National Health Service has been the matter of some historiographical disagreement. For an introduction to the differing opinions on the subject, see Charles Webster, 'Conflict and Consensus: Explaining the British Health Service', Twentieth Century British History, 1 2 (1990): 115-51; and Frank Honigsbaum, Health, Happiness, and Security: The Creation of the National Health Service (London: Routledge, 1989). See also John Stewart, The Battle for Health: A Political History of the Socialist Medical Association, 1930-51 (Aldershot: Ashgate, 1999).

[xlviii.] See Anne Oakley, 'Making Medicine Social', in Dorothy Porter (ed.), Social Medicine and Medical Sociology in the Twentieth Century (Amsterdam: Rodopi, 1997), 81-96. Significantly, in 1944, the Inter-Departmental Committee on Medical Schools, chaired by Sir William Goodenough, identified 'genetics' as one of the new scientific disciplines that should be incorporation into the new medical curriculum, as the entire medical establishment was reorganised during the period under consideration. See Goodenough, Report of the Inter-Departmental Committee on Medical Schools (London: H. M. S. O., 1944), 168.

[xlix.] See Pauline M. H. Mazumdar, Eugenics, Human Genetics, and Human Failings: The Eugenics Society, its Sources and its Critics in Britain (London: Routledge, 1992), 196-255.

[l.] See 'The Genetics of Cancer', British Medical Journal, 1948, Vol. 2: 86-88.

[li.] As Daniel Kevles has noted, 'phenylketonuria', a genetically determined biochemical imbalance that resulted in mental incapacity, provided Lionel Penrose with a model for a medically orientated human genetics that avoided the pitfalls of eugenic approaches to 'prevention'. See In The Name of Eugenics: Genetics and the Uses of Human Heredity (Berkeley: University of California Press, 1985), 177-78.

[lii.] Cuthbert E. Dukes, 'Research into Intestinal Polyposis', Lancet, 1953, Vol. 1: 44.

[liii.] See Daniel J. Kevles, In The Name of Eugenics: Genetics and the Uses of Human Heredity (Berkeley: University of California Press, 1985), 193-222.

[liv.] Polyposis Registry: Family 22: C. E. Dukes to patient, 7 August 1951.

[lv.] Tom Rowentree, 'Three New Families of Intestinal Polyposis', Proceedings of the Royal Society of Medicine, 43 (1950): 686-88.

[lvi.] Cuthbert E. Dukes, 'Familial Intestinal Polyposis', Annals of Eugenics, 17 (1952): 1-29, on 2-3.

[lvii.] Polyposis Registry: Family 4: C. E. Dukes note, 19 November 1953.

[lviii.] Polyposis Registry: Family 30: H. J. R. Bussey to M. Orr, 23 February 1977.

[lix.] On the persistence of eugenic discourse, see Diane Paul, Controlling Human Heredity, 1865 to the Present (Atlantic Highlands: Humanities Press, 1995), 124-25. The place of racial, as opposed to social, difference in British eugenic discourse has been usefully re-evaluated by Daniel Stone; see 'Race in British Eugenics', European History Quarterly, 31 3 (2001): 397-425. For an extensive discussion of the persistence of a racialised vision of the inhabitants of the poorest areas of Britain, such as the London East End, into the period considered here, and beyond, see instead Elizabeth Wilson, The Sphinx in the City: Urban Life, the Control of Disorder, and Women (Berkeley: University of California Press, 1991), 100-20. I am grateful to Teresa Young for alerting me to this continuity, at least among those people charged with slum clearance and urban renewal.

[lx.] Polyposis Registry: Family 3: C. E. Dukes note, 29 December 1960.

[lxi.] Polyposis Registry: Family 22: Letter to C. E. Dukes, 5 August 1951.

[lxii.] Dukes, 'Familial intestinal polyposis', 2. Here, the patients' and their realtives' responses to the medical professionals' understanding of their condition would seem to support Martin Richards' analysis of lay and professional discourses. See Martin Richards, 'Families, Kinship and Genetics', in Marteau and Richards, The Troubled Helix, 249-73; as well as Brian Wynne, 'Misunderstood Misunderstandings: Social Identities and Public Uptake of Science', Public Understanding of Science, 1 3 (1992): 281-304.

[lxiii.] Polyposis Registry: Family 44: H. E. Lockhart-Mummery to C. E. Dukes, 5 May 1952.

[lxiv.] Polyposis Registry: Family 14: A. M. O. Veale to C. E. Dukes, 27 December 1953.

[lxv.] Arthur M. O. Veale, 'Genetics, Carcinogenesis, and Family Studies', British Surgical Practice and Surgical Progress (1961): 169-185, on 178.

[lxvi.] John M. A. Northover, 'Imperial Cancer Research Fund Colorectal Cancer Unit', St. Mark's Hospital for Diseases of the Rectum and Colon, Annual Report (1984): 53-54, on 53.

[lxvii.] Polyposis Registry: Family 53: Patient to S. Ritchie, 11 January 1984. For a discussion of the place of genetic uniformity

in the production of chemical therapeutics for the treatment of cancer, which focuses however on the United States, see Ilana Löwy and Jean-Paul Gaudillière, 'Disciplining Cancer: Mice and the Practice of Genetic Purity', in Löwy and Gaudillière (eds.), The Invisible Industrialist: Manufactures and the Production of Scientific Knowledge (London: Macmillan, 1998), 208-49. See also Löwy's remarks about the differences between British and American approaches to cancer research during the period in question, in "Nothing More to be Done': Palliative Care versus Experimental Therapy in Cancer Research', Science in Context, 8 1 (1995): 209-29. Her differentiation seems to be borne out by some surgeons' opposition to the therapeutic trials in St. Mark's Hospital, an opposition articulated by reasserting the personal and exclusive relationship between the clinician and his or her particular patients.

[lxviii.] Arthur Veale's removal of 'familial adenomatous polyposis' into the laboratory, and the advantages it presented insofar as it located genetic investigations of this condition more squarely within the domain of clinical medicine, parallels Louis Pasteur's confrontation with sanitarians, as articulated by Bruno Latour in The Pasteurization of France (Cambridge, Mass.: Harvard University Press, 1988).

[lxix.] See H. J. R. Bussey and B. C. Morson, 'Familial Polyposis Coli', in R. W. Raven and F. J .C. Roe (eds.), The Prevention of Cancer (London: Butterworths, 1967), 141-45; and H. J. R. Bussey, Familial Polyposis Coli: Family Studies, Histopathology, Differential Diagnosis and Results of Treatment (Baltimore: Johns Hopkins University Press, 1975).

[lxx.] The difficulties confronting Arthur Veale bear a close resemblance to those confronting the oncologists discussed by Ilana Löwy and Jean-Paul Gaudillière in their essay on 'Disciplining Cancer: Mice and the Practice of Genetic Purity'. Such difficulties continue to this day, as 'modifier genes' have to be discovered to sustain the genetic determination of 'familial adenomatous polyposis'. See R. Houlston et al., 'Explaining Differences in the Severity of Familial Adenomatous Polyposis and the Search for Modifier Genes', Gut, 48 1 (2001): 512-21.

[lxxi.] See Raphael Samuel, Theatres of Memory: Past and Present in Contemporary Culture (London: Verso, 1994); and Anthony Camp, 'Family History', in David Hey (ed.), Oxford Companion to Local and Family History (Oxford: Oxford University Press, 1996), 168-174.

[lxxii.] Kay Neale, personal communication, 27 June 1995.

[lxxiii.] Polyposis Registry: Family 53: Patient to S. Ritchie, 11 January 1984.

[lxxiv.] Polyposis Registry: Family 4: S. V. Hodgson to patients, 27 January 1992.

[lxxv.] On the 'new' genetics and memories of eugenics, see Anne Kerr, Sarah Cunningham-Burley and Amanda Amos, 'Eugenics and the New Genetics in Britain: Examining Contemporary Professionals' Accounts', Science, Technology, &

Human Values, 23 2 (1998): 175-98.

[lxxvi.] Northover, 'Imperial Cancer Research Fund colorectal cancer unit', 39.

[lxxvii.] Polyposis Registry: Family 4: S. V. Hodgson to J. Nicholls, 25 September 1992. See also Rayna Rapp, 'Refusing Prenatal Diagnosis: The Meanings of Bioscience in a Multicultural World', Science, Technology, & Human Values, 23 1 (1998): 45-70.

[lxxviii.] On the significance of religious beliefs in patients' acceptance of, and responses to genetic testing, see A. C. Dudok deWit et al., 'Predicting Adaptation to Presymptomatic DNA Testing for Late Onset Disorders: Who will Experience Distress?', Journal of Medical Genetics, 35 9 (1998): 745-54.

[lxxix.] Polyposis Registry: Family 33: S. V. Hodgson, note, 22 November 1993.

[lxxx.] For example, the British government is currently seeking to encourage the British public to opt for private insurance policies, so as to relieve the increasing financial pressures on the National Health Service. In the meantime, insurance companies are seeking the government's permission to use genetic tests for 'familial adenomatous polyposis', among seven key heritable diseases, to cost these insurance policies. It remains to be seen how the increased cost of having a child who will probably have to undergo surgical treatment to remove the polyps that will infest his or her colorectal tract during teen-age years will affect parents' decisions. See James Meek, 'Insurers to Take on Government over Gene Tests, The Guardian, (13 October 2000), 13.

[lxxxi.] Vines, 'Star of the big screen'.

[lxxxii.] Strikingly, Teresa Marteau's account of the differences between her own and the patients' understanding of their condition rehearse historical divisions within the 'professional' understanding of the relationship between heredity and environment. See Paolo Palladino, 'People, Institutions, and Ideas: American and British Geneticists at the Cold Spring Harbor Symposium on Quantitative Biology, June 1955', History of Science 34 4 (1996): 411-50. From this perspective, Anne Kerr, Sarah Cunningham-Burley and Amanda Amos' analysis of the divisions between 'lay' and 'professional' understanding of heredity is perhaps more appropriate than that proposed by Martin Richards, in 'Families, Kinship and Genetics'. See 'Drawing the Line: An Analysis of Lay People's Discussions about the New Genetics', Public Understanding of Science, 7 2 (1998): 113-33.

[lxxxiii.] For a more general discussion of the problems involved in the construction of 'pedigrees', see Claudia Castañeda, 'Der Stammbaum. Zeit, Raum und Alltagstechnologie in den Vererbungswissenschaften', in Sigrid Weigel (ed.), Genealogie und Genetik, (Berlin: Akademie Verlag, 2002), 57-69; and Yoshio Nugaka and Alberto Cambrosio, 'Medical Pedigrees and the

Visual Production of Family Disease in Canadian and Japanese Genetic Counselling Practice', in Mary Ann Elston (eds.), The Sociology of Medical Science & Technology (Oxford: Blackwell, 1997), 29-55.

[lxxxiv.] This conclusion contradicts Pauline Mazumdar's argument that the advent of the National Health Service marked the end of eugenic discourse. See Eugenics, Human Genetics, and Human Failings, 256-68. For another discussion of how clinical pathologies are transformed into genetic diseases, and the implicit methodological, if not ideological, commitments, see Anne Kerr, '(Re)constructing Genetic Disease: The Clinical Continuum between Cystic Fibrosis and Male Infertility', Social Studies of Science, 30 6 (2000): 847-94.

[lxxxv.] Rayna Rapp speaks to this agency of patients in 'Refusing Prenatal Diagnosis', esp. 67-8.

[lxxxvi.] The more recent controversy over deCODE Genetics' purchase of the medical records of the entire population of Iceland should once again remind us that the promises of molecular genetics are inseparable from genealogical investigations and their attendant political problems. See A. Berger, 'Private Company Wins Rights to Icelandic Gene Database', British Medical Journal, 1999, Vol. 1: 11; and R. Haraldsdóttir, 'Icelandic Gene Database Will Uphold Patients' Rights', British Medical Journal, 1999, Vol. 1: 806. For a more general discussion of the link between 'genes' and 'networks of kinship', especially as it is transformed, and perhaps invalidated, by the dynamics of global capitalism, see Sarah Franklin, Celia Lury and Jackie Stacey, Global Nature, Global Culture (London: Sage, 2000), 68-93.

[lxxxvii.] De Certeau, The Practice of Everyday Life, 45-49. See also Michel Foucault, 'Questions on Geography', in Colin Gordon (ed.), Power/Knowledge: Selected Interviews and Other Writings by Michel Foucault (New York: Prentice-Hall, 1980), 63-77.

[lxxxviii.] On the links between the language of 'efficiency' and 'eugenics', see Geoffrey R. Searle, The Quest for National Efficiency: A Study in British Politics and Political Thought, 1899-1914 [1971], (London: Ashfield,1990), 60-67.

[lxxxix.] This problem is opened to debate by the now famous exchanges in Andrew Pickering's Science as Practice and Culture between Harry Collins and Steven Yearley, on the one hand, and Michel Callon and Bruno Latour, on the other hand. As Pickering notes in his introductory remarks to Science as Practice and Culture, the debate raises difficult ontological, if not metaphysical problems, which, however, are not fully explored. See Pickering's Science as Practice and Culture (Chicago: University of Chicago Press, 1992), 17-22 and 301-89.

[xc.] Michel Foucault, 'Politics and the Study of Discourse', in Burchell et al., Foucault Effect, 53-72.

[xci.] See Michel Foucault, Madness and Civilization: A History of Insanity in the Age of Reason [1961] (New York: Vintage Press, 1973). The different celerities of changes in 'knowledge' and 'practice' concerning those liminal figures we now call

the 'mad' allowed for dislocations, tensions, and eventual ruptures. These ruptures marked the temporality of the history of 'madness'. Oddly, however, Foucault never examined the implications of this understanding of 'history' and the 'event' for the concepts of 'time', and, of course, 'memory'. At best, he argued that time is no longer important to understanding modern political order. See Foucault, 'Questions on Geography', 69-71.

[xcii.] Jacques Derrida, 'Cogito and the History of Madness [1964]', in Derrida, Writing and Difference (London: Routledge, 1978), 31-63. See also Michel Foucault, 'My Body, this Paper, this Fire [1972]', in Faubion (ed.), Michel Foucault, Vol. 2, 393-417.

[xciii.] Michel Foucault, Discipline and Punish: The Birth of the Prison [1975] (London: Penguin, 1991).

[xciv.] Gary Gutting, Michel Foucault's Archaeology of Scientific Reason (Cambridge: University of Cambridge Press, 1989), 55-110.

[xcv.] See Foucault, History of Sexuality, 100-2.

[xcvi.] Michel Foucault, as quoted by Paul Rabinow, in Essays on the Anthropology of Reason, 92. Significantly, Foucault was reacting to the protracted arguments with Jacques Derrida, although Derrida himself remains unnamed. See 'Truth and Power', in Gordon, Power/Knowledge, 109-33, esp. 127.

[xcvii.] Significantly, Paul Rabinow turns to Gilles Deleuze to articulate his critique of Michel Foucault, overlooking, however, the dynamics of 'de-territorialization' and 're-territorialization' that mark the temporality of Deleuze and Félix Guattari's historical narrative, most notably in A Thousand Plateaus: Capitalism and Schizophrenia [1980] (London: Athlone, 1988).

[xcviii.] In French DNA, Paul Rabinow turns to Jacques Le Goff's The Birth of Purgatory to articulate his critique of the 'hermeneutics of suspicion' and then call for a displacement of the 'will to knowledge' by a 'will to experiment' that is more open to the 'future'. See French DNA, 17-23. Yet, as Paul Fletcher has noted, one can also read Le Goff's The Birth of Purgatory and Your Money or Your Life rather differently than Rabinow does. Arguably, the invention of the 'purgatory' coincides with that of 'interest', which lends capitalism one of its chief characteristics, namely, the predetermination and hence foreclosure of the future. See also Éric Alliez, Capital Times: Tales from the Conquest of Time (Minneapolis: University of Minnesota Press, 1996), 1-25. In other words, the cost of not thinking about the causal dynamics that underlie Deleuze and Félix Guattari's historical narratives is that Rabinow fails to notice that there is no future in the age of 'biosociality'. The claim that the 'will to experiment' is open to the 'future' is then meaningless.

[xcix.] Foucault, History of Sexuality, 157.

[c.] Judith Butler, 'Revisiting Bodies and Pleasures', in Vikki Bell (ed.), Performativity & Belonging (London: Routledge,

1999), pp 11-20.

[ci.] Reacting to Michel Foucault's ideas on the relationship between power and politics, Jacques Rancière turns to classical constitutions and analyses of politics. He argues that politics exists only when 'discourse' confronts the violence in which it must necessarily be grounded, but which also is, by definition, always external to its domain of considerations. In other words, politics is only possible where there is an aporia, an impossibility of calculation; Dis-agreement: Politics and Philosophy (Minneapolis: University of Minnesota Press, 1998), pp 1-19.

[cii.] According to Jacques Rancière, the only positive asset that the demos can bring to the polis is the freedom into which they are born, but this freedom is a quality shared with the aristoï, the virtuous, and oligoï, the wealthy. The demos is thus either everything, which is unacceptable to the aristoï and oligoï, or it is nothing, which, of course, is unacceptable to the demos. See Dis-agreement, 9.

[ciii.] Interview with members of family 14, 10 July 1997. See also Rabinow, French DNA; and Rabeharisoa and Callon, Le Pouvoir des Malades.

[civ.] Tom Shakespeare, 'Back to the Future? New Genetics and Disabled People', Critical Social Policy, 46 (1995): 22-35, on 34.

[cv.] Significantly, Michael Lynch has recently turned to Jacques Derrida's Archive Fever to articulate an ethnomethodological account of memory, which removes any traces of the 'transcendental'. See 'Archives in Formation'; and Derrida, Archive Fever: A Freudian Impression (Chicago: University of Chicago Press, 1996). Yet, in so doing Lynch, like Tom Shakespeare, overlooks the difference between 'difference' and 'différance'. To Derrida, this is a subtle, but crucially important distinction. I am grateful to Michael Dillon for alerting me to this distinction, whose elision he finds fundamentally important for understanding contemporary political discourse. See 'The (De)Void of Politics: Jacques Rancière's Ten Theses on Politics', paper presented at 'On The Shores of The Political: A Colloquium on Jacques Rancière's Political Thought', University of California - Los Angeles, Los Angeles, 19 October 2001.

[cvi.] Arguably, the concepts of 'actor-network' and 'discourse', at least as they are re-formulated by Paul Rabinow, owe much to Gilles Deleuze and Félix Guattari's concept of the 'body without organs'. This paper has sought to question what exactly constitutes 'desire', the entelechy that impels the constitution of the 'body without organs'. See Anti-Oedipus: Capitalism and Schizophrenia [1972] (London: Athlone Press, 1984). For a discussion of the need to revitalise 'actor-network theory' that touches on this issue, see Steven D. Brown and Rose Capdevila, 'Perpetuum Mobile: Substance, Force and the Sociology of Translation', in John Law and John Hassard (eds.), Actor Network Theory and After (Oxford: Blackwell,

1999), 26-50.

[cvii.] One way in which to start such an inquiry might be to contrast Alliez, Capital Times, 27-74 with Brown and Capdevila, 'Perpetuum Mobile', 42-45.