

The Flesh Made Word: Banking the Body in the Age of Information

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Abstract

The John Moore case in the United States and the Alder Hey scandal in Britain raised many urgent questions about the legal and ethical status of human tissue collections. This article intervenes in the current debates by posing an ontological question about tissue banking. The present discussions of the regulation of tissue archiving often rely upon a crisp, yet ill-defined, distinction between bodily 'material' and medical 'information', each bringing with it different legal and ethical considerations. Arguing that the distinction is actually difficult to draw and in urgent need of clarification, we propose that the term 'information' is too broad and vague to do the necessary work and suggest replacing it with a carefully theorized account of the precise ontological differences between material and textual resources. In the second half of the article we explore one particular case of the extraction of information from human tissues—the DNA sequence. We conclude by deploying the definitions reached in the first section in an effort to clarify some of the legal and ethical concerns about 'genetic information'.

Keywords Alder Hey, Data Protection, DNA Databases, Genetic Information, Medical Records, Tissue Banking

Cathy Gere did her PhD in the Department of History and Philosophy of Science at Cambridge University. This article arises out of her post-doctoral work: a project funded by the Wellcome Trust, led by co-author Bronwyn Parry, and based at King's College Cambridge, which used the Addenbrookes Hospital Brain Bank Laboratory as a case study through which to examine the history and ethics of tissue archiving. Recent related publications include a special issue of *Studies in History and Philosophy of Biological and Biomedical Sciences* on philosophical, historical, cultural and aesthetic aspects of the famous 'Brain in a Vat' thought experiment. Dr Gere is currently a visiting professor at the Morris Fishbein Center for the History of Science and Medicine at the University of Chicago, where she teaches history of medicine, history of the neurosciences and history of bioethics.

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In the last years of the twentieth century an invisible aspect of routine medical practice in Great Britain suddenly became painfully visible. During the course of a public inquiry into what had gone wrong at the paediatric cardiac surgery unit of Bristol Royal Infirmary, it became apparent that the hospital routinely retained the hearts of children who had died during treatment or surgery. There was an outcry in the press and hospitals started to receive phone calls from parents. One particular institution soon became the focus of attention. It turned out that the Alder Hey Hospital in Liverpool had, for a period in the late 1980s and early 1990s, engaged in a practice of retaining, not only the hearts, but many of the internal organs of children who had died there, without the explicit consent of the parents. On 3 December 1999 the new HM Coroner for Liverpool suggested that this type of organ retention was unlawful. There was another media scrimmage, and the government responded by announcing that there would be an independent inquiry into organ and tissue retention at Alder Hey.

In addition to the findings of the public inquiry, a cascade of articles poured forth, pondering the ethics and legality of human tissue archiving. The Medical Research Council and the Royal College of Pathologists published new guidelines for the use of human tissue (Medical Research Council, 2001; Royal College of Pathologists, 1999). The Human Tissue Act of 1961 was found to be wholly inadequate and the provisions of the act were suspended while the legislation was revised. The new Human Tissue Act became law in November 2004, and its provisions are expected to be brought into force in April 2006 (Parry, 2005).

In the United States a similar flurry of guidelines, directives, recommendations and ethical musings followed a long legal battle. In this famous case, John Moore, a leukaemia patient whose tissues had been used by his doctor to develop a cell line, sued the doctor in question for a share of the profits. The doctor had discovered that Moore's spleen cells produced an unusual blood protein that might be used to develop an anti-cancer agent, and, in January 1983, the doctor and his research assistant filed a patent application. In 1984, Moore brought a lawsuit against his doctor, the regents of UCLA and the pharmaceutical companies that licensed the 'Mo' cell line.

In 1990, the California Supreme Court ruled that Moore's doctor had breached his fiduciary duty by not revealing a research and financial interest in his patient's cells (the so-called 'check-ups' that he insisted Moore have every few months were in fact for the purposes of harvesting more of his cells and investigating their properties). However, the court also denied Moore's claim to ownership of the cells removed from his body, arguing that since human biological materials play a critical role in medical research, granting a patient proprietary rights would hinder the advance of science by restricting access to the necessary raw materials (Office of Technology Assessment, 1987: 26).

Between them, the John Moore case and the Alder Hey scandal raised a host of questions, touching on many key areas of dispute in medical ethics. In Britain the principal issue raised by the events at Alder Hey was about informed consent: how was it that the consent procedure had broken down so badly that the parents involved had no idea that their children's internal organs were to be archived by the hospital? In America, the main political fall-out from the John Moore case concerned commodification: now that biotechnology had turned the human body into an exploitable resource potentially worth billions of dollars, who, exactly, should be allowed to profit from its products?

This article takes a step back from these urgent political and social questions to examine an ontological question about tissue banking, one that we believe has far-reaching implications for many of the other issues at stake in these disputes. We have found that the literature debating the rights and wrongs of human tissue archiving is marked by a systematic but unacknowledged lack of clarity about one important question. In arguing the merits and demerits of different regulatory regimes for the collection, storage, use and disposal of human tissue, this literature generally relies upon a clear-cut distinction between *material* resources derived from the human body on the one hand (governed by laws regarding property and the body and informed consent procedures) and, on the other, medical *information* derived from patients and their tissues (the domain of data protection or confidentiality legislation). We aim to show that this distinction is actually far from clear and is in urgent need of elucidation.

Here, for example, is the American bioethicist Sheri Alpert meditating on this very question in her article ‘Privacy and the analysis of stored tissues’:

To some extent, it may seem rather artificial to split the use of the tissues from the use of the information gleaned from the tissues. After all, it is largely the information that will be gleaned from the tissues that can have the greatest potential to harm or help individuals or groups. And the two sets of concerns certainly overlap. However, different types of privacy concerns arise from each type of use. For instance, in the case of how the tissues are used, the informed consent process generally sets out the parameters under which tissues are provided by the tissue source and used at least by the initial recipient. Once the tissue is obtained, confidentiality rules protecting informational privacy interests come into play to safeguard the information that results from the analysis of the tissues and ensure that the tissues are used in a manner consistent with the informed consent. (Alpert, 2000: 15–16)

Alpert confidently asserts that there are two ‘types of use’, bringing in their train ‘two sets of privacy concerns’. Her article is one of the few accounts of the ethics of human tissue archiving to grapple head-on with the question of material versus informational resources, but her analysis raises more questions than it answers. At no point does she define *what* the two ‘types of use’ (a remarkably unhelpful formulation) might be, or suggest exactly *when* one set of concerns might take over from another (when, in other words, the ‘confidentiality rules’ should ‘come into play’), or, indeed, argue *why* these ‘rather artificial’ distinctions should matter. In this article we aim to take a close analytical look at the practices of collecting, storing and using human tissues for medical research in order to clarify when a body becomes a ‘body of information’, and to explain why we should care.

‘Flat material’: tissue blocks and slides in the medical record

In the wake of the Alder Hey scandal and the John Moore case, confusions quickly arose in differentiating between the ‘informational’ and the ‘material’ components of human tissue archives. These complications arose not, as one might expect, in relation to information-age technologies such as gene sequencing, but over tissue archives using techniques originating in the nineteenth century. In this section we examine the problems that have arisen in defining the informational status of tissue blocks—small amounts of tissue embedded

in paraffin wax—and tissue slides—extremely thin slices cut from the blocks and mounted on glass microscope slides—artefacts that are routinely retained in pathology departments as part of the patients’ medical records. The apparent simplicity of the technologies involved will allow us to advance some preliminary theoretical considerations.

In the course of the Alder Hey crisis:

Another issue emerged. Some parents became aware that Alder Hey was still retaining blocks and slides taken from organs and requested their return. Alder Hey’s response has been inconsistent, depending on how they perceived the likely reactions of parents. Sometimes they have denied the existence of blocks and slides. On occasions they have returned them. *Sometimes they have claimed that they cannot be returned, as they constitute a medical record, on other occasions they have claimed that the blocks and slides constitute a medical record, which may not be returned until ten years have elapsed.* The policy of openness and honesty was compromised. (Royal Liverpool Children’s Inquiry, 2001: 8.3, our emphasis)

So it seems that, on the one hand, for many of the parents whose children’s organs had been retained at Alder Hey, tissue blocks and slides were unambiguously parts of the body, corporeal entities endowed with all the spiritual and emotional significance carried by the human remains of beloved family members. For most members of the medical establishment, on the other hand, ‘blocks and slides constitute a medical record’, something to be filed with case notes and temperature charts.

The Alder Hey Inquiry condemned the attitude of medical professionals in this regard—‘the policy of openness and honesty was compromised’—effectively capitulating to the emotional atmosphere surrounding the scandal. The funeral for repatriated microscope slides thereafter became the emblematic divisive ritual of the crisis, giving doctors further proof of the parents’ hysteria and confirming for the parents the medical establishment’s lack of feeling. As the first storm receded, however, the Retained Organs Commission repented of their capitulation, and admitted that the policy of returning tissue blocks and slides was not ‘necessarily based on sound legal or ethical arguments’ (Retained Organs Commission, 2002: 13). The Commission then set up a consultation process designed to clarify the status of these baffling objects.

In the wake of the John Moore case in the United States the same ambiguity manifested itself, as pathologists struggled to define their rights and responsibilities relating to archives of human tissues. In 1999, after organizing and engaging in a long-term consultation process, a coalition of pathologists’ organizations published a policy statement ‘for uses of human tissue in research education and quality control’. The statement included this assertion:

Specimens (referred to also as tissues and including cells and bodily fluids) removed from patients and sent to the pathology laboratory for examination essentially become part of the patient’s medical record, either through processing into durable materials (e.g. *slides, blocks, and reports*) or through maintenance in some storage form (e.g. preserved in formalin; frozen; tissue culture). The laboratory that provides the primary diagnostic analysis of specimens is responsible for the maintenance and integrity of this part of the medical record. (quoted in Royal College of Pathologists, 1999: 8, our emphasis)

For American pathologists, the patient's record is divided into 'durable materials', in which slides, blocks and reports are grouped together, and 'stored materials' including frozen and fixed tissues. Again, as in the Alder Hey case, blocks and slides are united with written materials, this time by virtue of the seemingly arbitrary criterion of 'durability'. This arbitrariness is further complicated by the fragmented and inconsistent legal situation regarding tissue ownership, tissue block possession and slide possession in the US. The courts in some states, for example, have issued regulatory decrees indicating that *the information* in the slides and blocks belongs to the patient, but *the actual slides and blocks* are the property of the original institution. Others have indicated in their rulings that everything is the property of the patient (LaVolsi, 1995: 260–261).

In pathology departments, it seems, various different kinds of archive are all lumped together under the rubric of 'record', with bits of tissue treated like informational resources. But at Alder Hey many of the bereaved parents understandably failed to appreciate the distinction between a tissue block stored in one part of the hospital and an organ stored in another part, claiming back every scrap of bodily material. In some American states the same problem arose in reverse as the courts tried to reconcile the hospitals' need to retain the samples with the patients' right to control the information contained within the material. But what does it mean, exactly, to separate the information contained in the material from the material itself? How is it that these apparently inextricable components of the archive can actually belong to different constituencies?

The term 'information' is a keyword in medical ethics, (think of 'genetic information' or 'informed consent'), but it turns out to be a slippery concept. It is a word with many different meanings, ranging from the highly technical—'a non-accidental signal in a communication system'—to the very broad—'knowledge derived from study, experience or instruction'. In the context of the present discussion, information is something that medical specimens are said to 'contain'. But how can we make sense of this?

The philosopher Fred Dretske has coined the phrase 'nuclear information', as in something 'capable of yielding knowledge', something that *contains within it* the means to glean such knowledge, just as the dance of bees contains information about where nectar can be found, or a tree contains information about its age in the form of rings that could be counted in a cross-section of its trunk (Dretske, 1981: 45). It is in exactly this sense that we talk about the information *in* human tissue samples. Under this definition, the word 'information' denotes relations of cause and effect that leave traces—as in Dretske's tree rings example. Information is not so much a discrete substance or essence, but a potential, immanent in everything that is embedded in knowable cause-and-effect relations.

This certainly seems to capture the sense in which human tissue 'contains' information, but it does not help us clarify at what point and in what form this immanent, potential stuff, with which the whole world seems to hum, needs to be legislated for *as information*. Dretske asserts that his 'nuclear information' is information in 'the very same sense in which we speak of books, newspapers and authorities as containing or having information about a particular topic...' (1981: 45). For our purposes, however, we clearly need to *differentiate* between tree rings, experts on tree rings and newspaper articles about tree rings. A preliminary step in defining the boundary between material and informational resources in medical archives might thus be to put aside the over-broad concept of 'information' and to distinguish instead between *texts* and *objects*.

Text is certainly a narrower concept than information. One way of thinking about it is to define text as a symbolic system that can be transferred from one medium to another without any loss of meaning. Text is what we might call ‘medium-indifferent’. A haiku is still the same poem whether chiselled into the rock on the side of a mountain or scratched into a rose petal with the point of a pin. The transfer of meaning across these disparate materials is dependent upon the symbolic conventions of script and language, units of meaning whose potential detachment from one material platform to another is irrelevant to their content.

Data protection, freedom of information and confidentiality legislation are all predicated upon this quality of medium-indifference: it is essential for the implementation of the British Data Protection Act, for example, that the information in question can be *copied*. These regulations are about controlling the flow of something that can be reproduced, transmitted and disseminated. In order to clarify when these regulatory regimes apply in the case of tissue banking, perhaps we need, therefore, to examine what steps are taken to render knowledge about the natural world into a medium-indifferent form.

We need, in other words, to examine the processes involved in the *extraction* of information from the world, the manipulations and translations that turn a bit of the world into knowledge, and then into communicable knowledge. A tree can be said to contain information about its age, but it is important to note that this biography of the tree’s life is not immediately visible: the tree has to be cut across a section of the trunk to be interpreted in this way. Only when a clean cross-section has been exposed, is it possible to read the tree’s record of the seasons. Extracting information, then, requires that the natural world be manipulated in such a way that the information becomes *legible*. In order to understand the transformation from bodily to informational resources in tissue banking we need to be sensitive to the moment at which a specimen crosses what we might call the ‘threshold of legibility’.

Of course, legibility thresholds will vary from reader to reader. To someone knowing the appropriate cause-and-effect relations, the cross-section of a tree trunk yields the necessary information about the tree’s age. Someone else might require that the cross-section be given linguistic extension: an explanation of the relation between the number of rings and the age of the tree. The end point of this process might just be the statement ‘the tree was 59 years old’. So on the one side we have an object—the tree—and on the other side we have a text—‘the tree was 59 years old’. But how do we sort out all the stages in between—the cut tree, the photograph or drawing of the tree’s cross-section, the uninterpreted statement of the number of tree-rings?

Suggestively, in the tree-rings example, there seems to be a connection between crossing a threshold of legibility and reaching a state of medium-indifference: the tree-rings can (by the person in possession of the right understanding of cause-and-effect relations) be *read* on the surface of the cross-section, no further manipulations are required and the surface could be drawn or photographed and translated into two dimensions without any loss of meaning. Perhaps the connection between legibility and medium-indifference is not so surprising. It makes sense that there should be a relationship between legibility and communicability and between communicability and transmissibility.

Working with this property of ‘medium-indifference’ we seem to have arrived at a pragmatic way of distinguishing between what are loosely known as ‘material’ and

‘informational’ resources. There appears to be a usable ontological distinction between information-containing objects, resplendent in all their three-dimensional uniqueness, and information-bearing surfaces, transmissible in all their two-dimensional replicability. (It should be noted here that these definitions do not reside in a Platonic realm of absolutes but are produced by technological changes, and are subject to the flux of history.)

Dretske points out that one thing that distinguishes symbolic representations of information from the kind of information that resides as ‘raw material’ in the world is the possibility of *falsity*. In his consideration of ‘artefacts such as maps, diagrams and charts’ he asks ‘How is it possible for the coloured lines, dots and areas on the paper to *misrepresent* certain features of an area’s geography?’ (1981: 190). An area’s geography cannot misrepresent itself. It is only through the process of information extraction and then representation that the possibility of falsity comes into play.

A crucial link in the flow of information (from the physical terrain to the arrangement of marks on paper) is the map maker himself. He constitutes a link in the communication chain in which information can be lost through ignorance, carelessness, or deceit. (1981: 191)

This is another feature of extracted, processed, replicable information that is implied in the provisions of Data Protection Act. Section 14 of the 1998 Act states that the court may ‘order the data controller to rectify, block, erase or destroy’ information that the court deems to be inaccurate.

So, can we apply the criterion of medium-indifference to the case of tissue blocks and slides to properly distinguish between material and informational resources? Tissue blocks and slides clearly cannot be *copied* without losing some of their meaning. They are singular objects whose informational value lies in their corporeality, their intimate connection with the body from which they were taken. But their artefactual nature, their high proportion of man-made to natural substances, the slicing and staining that makes slides accessible to interpretation by the trained observer and their central importance to the normal, everyday procedures of medical record-keeping, mean that they are retained by pathology departments as though they are texts rather than body parts.

We said above that microscope slides could not be copied without a loss of meaning. But let us for a moment examine the possibility that a very high-resolution digital photograph of a slide that allowed for magnifications equivalent to a normal microscope could, at least for most purposes, stand in for the slide itself. A microscope slide is a highly engineered artefact that has achieved a threshold of legibility such that it could be rendered in two dimensions and still fulfil most of its functions. Why not, then, photograph the slides and return the originals to the relatives of the deceased? The answer is that microscopic examination does not actually exhaust the range of ‘readings’ to which a slide may be subject. The possession of the thing itself, and even more of the block from which it was sliced, provides for unforeseen or unprecedented manipulations to be carried out, should the need arise.

There are many such uses. First, retrospective examination of tissue archives can shed much light on new diseases, or diseases that have been poorly understood, misdiagnosed or overlooked. In one celebrated example, a collection of the brains of psychiatric hospital inmates gathered over many years starting in the 1950s (the Corsellis collection) was

consulted in the 1990s to establish whether new variant CJD was actually a new disease. Second, technical developments can allow archived materials to be subjected to kinds of analysis not available at the time of collection. As the techniques for extraction and replication of DNA and RNA have improved over the years, for example, it has become possible to perform genetic analysis on decades-old specimens.

Third, and perhaps most important, the retention of tissue blocks and slides allows the work of doctors to be *checked*. Unlike the information contained in a text or representation, the information in corporeal samples cannot in itself be false (although it can, of course, be mislabelled and/or misinterpreted). The post-mortem is the first moment at which the diagnosis of the patient can be checked against the signs of the disease. The possibility of retrospective analysis, often dependent upon the three-dimensional specificity of the tissue itself, is absolutely central to the evidentiary value of the medical record.

Museum curators talk about a category of objects known as ‘flat material’. Posters and pamphlets fall into this category, objects once mass-produced and now rare, objects that have ceased to be just the carriers of their message and have become valuable in, so to speak, the three dimensions of their singularity and scarcity, as opposed to the two dimensions of their status as mere surfaces for the message they carry. (Authenticity, in these cases, can be tested in a laboratory deploying the three-dimensional qualities of the material itself.) The tissue blocks and slides retained at Alder Hey and elsewhere as part of the medical record could be understood as having been archived as a biomedical version of flat material, having undergone a reverse process of this transformation from two to three dimensions. Although they are singular objects, whose range of potential meanings is bound up with their retention of the physical characteristics of flesh, they are also records: microscope slides are highly processed, legible entities whose surfaces carry information that can be read without further manipulations.

Tissue blocks and slides are archived in pathology departments alongside X-ray films, and are regarded as an integral part of every patient’s medical record. Like manuscripts or first editions they seem to hover somewhere between texts and objects. But the value of these objects resides in their singularity and three-dimensionality. Photographs of slides, however fine their resolution, do not enable all the various kinds of retrospective analysis for which they might be retained. For the purposes of legislating these artefacts there is no dodging the fact that they are bodily material and not texts. They are not mere surfaces; they do not exhibit the crucial quality of medium-indifference that makes text the transferable, transmissible thing that it is.

In the wake of the Alder Hey scandal it might seem legislatively pragmatic to define tissue blocks and slides as texts, thus draining them of the emotional significance attached to physical samples. We hope to have shown why that it is neither possible nor desirable. The crucial issue at stake is that the legislation that governs the collection, storage and use of human tissue must encompass the fact that some tissue archives are a *necessity*, part of an accountable medical system under the responsible stewardship of pathology departments.

So why does it matter whether something is stored in a material or a medium-indifferent form? What are the relevant differences between the two different types of resources for the purposes of legislation and ethics? In a material form, the tissue is replete with unrealized informational potential: it is illegible to one degree or another, unpredictable, capable of

yielding unexpected insights, and incapable of falsehood. As a research resource it is finite and may be destroyed in the course of being manipulated to reveal its properties. It can be fragmented and shared, but it cannot be copied and disseminated (for the exceptions to this generalization, see below). A tissue sample may have emotional resonance for the person from which it was taken or for his or her bereaved.

In a medium-indifferent form the information in the sample is often ready to be used—to be published and/or acted upon. Information stored in a medium-indifferent form can be transmitted to an infinite number of interested parties without itself being depleted. Its legibility may be such that it can be interpreted by lay-people such as insurers. Texts and representations may be false or inaccurate, they may need to be checked against the more reliable testimony of physical samples. The emotional investments in a text or representation are likely to be very different from those in a material sample.

There does seem to be a case for legislating for material and textual resources differently, but the relevant differences may not be the ones that are presently assumed. At the beginning of this article we quoted Sheri Alpert, who argued that informed consent procedures only covered the obtaining of the tissue samples, and that confidentiality legislation then had to take over once the information had been extracted from the samples. This cannot be right. Informed consent procedures must cover the uses of the tissue across the whole process of being transformed into legible, medium-indifferent artefacts and used in research. In this case the division is artificial and irrelevant. As we already mentioned, however, data protection and freedom of information legislation is predicated on the information being available in a replicable format. Here, the criterion of medium-indifference provides exactly the framework required to distinguish which elements of the archive can be covered by such regulations. Laws against the trade in body parts, on the other hand, get some of their bite from the opposite qualities of singularity and scarcity inherent in material tissue (hence the exceptions made for painlessly replaceable substances like hair, blood and semen). Privacy legislation can only properly apply to resources that are legible: unless the information to be protected can be understood by another party, privacy cannot be said to have been violated. Once we replace the vague notion of ‘information’ with the criterion of medium-indifference, we can get a grip on why and under what circumstances different regulatory regimes and ethical considerations should apply.

Raw data: the DNA archive

The new Human Tissue Act (2004), which was drawn up in response to the events at Alder Hey, lays down stringent rules for obtaining consent for the removal, storage and use of human tissue without distinguishing between material and informational resources. In the Act ‘controlled material’ is everywhere defined as ‘any material which consists of or includes human cells’. There is, however, an exception: parts of the Act outline in great detail the provisions governing just one type of information that can be obtained from human tissues—the extraction, notation and analysis of DNA sequences (Human Tissue Act, 2004: part 3, section 45, pp. 28–29, and schedule 4, pp. 49–54). In this second section, we would like to revisit a long-debated question: why, out of all the ways that human tissue

can be analysed, is the analysis of human DNA considered such a special case? Can our exploration of the intricate relationship between objects, texts and information help to shed any light on ethical and regulatory concerns about ‘genetic information’?

There is a widespread sense that the phrase ‘genetic information’ describes something uniquely potent and sensitive, but the vagueness of the word ‘information’ is here compounded by the wideness of the term ‘genetic’, and most commentators begin by pointing out that ‘genetic information’ includes things like eye colour that cannot be said to be in need of special protection. So difficult has it been to reach a consensus on what kinds of things should be included under this rubric, that, in the United States, it is an oft-lamented fact that every new bill filed in an attempt to prohibit the misuse of genetic information deploys a different definition of its central terms (Trautwein, 2001). We would like to argue that some clarity can be brought to this problem by attending to the processes and transformations that render the genetic information contained in human tissues into medium-indifferent forms. The importance and sensitivity of DNA research stems from the rich and complex relationship between the genetic information contained in human tissues, and the artefacts—DNA sequences—that we create as one step towards rendering that information legible.

One argument often raised for the special status of DNA research is that the DNA molecule ‘contains information’ in a different and stronger sense than any other part of the natural world. Because DNA itself is *actually* a text, so the argument goes, the long chains of letters of which genetic sequences are composed are metaphysically identical with the ‘genetic essence’ of the organism from which they are derived. As geneticist Walter Gilbert wrote, ‘Three billion bases of sequence can be put on a single compact disc (CD) and one will be able to pull a CD out of one’s pocket and say, “Here is a human being; it’s me!”’ (Gilbert, 1992: 84–85). Propelled by the resulting anxieties about identity and confidentiality, arguments are then mounted for some sort of recognition of the exceptional status of DNA in law and ethics.

So, are there grounds for assigning human DNA any special metaphysical status as the informational essence of a person? Part of the seductiveness and appropriateness of the idea of DNA-as-text inheres in one quality of text that we have already discussed: replicability. The double helical structure of DNA—the way that the two strands fit together through the phenomenon of base-pairing—provides the mechanism for self-replication. Harnessing this characteristic has made possible a series of techniques that seem at first blush to undermine an assertion made in the first part of this article. We proposed that one feature that distinguishes corporeal material from text is that the former cannot be *copied*, yet cloning techniques such as polymerase chain reaction and cell lines result in biological materials that seem to partake of some of the reproducibility, immortality and transmissibility of text.

Note that, while the products of cloning technologies are by definition reproducible, they are far from medium-indifferent. In each case the correct medium kept at the correct temperature is, in fact, the *basis* of the technique. Cell lines are cells that grow and replicate outside the living organism by being cultivated in the right environment *in vitro*. Polymerase chain reaction is a technique for copying strands of DNA using chemical reagents and minute changes in temperature to stimulate the replication process. Furthermore, the products of cloning techniques are, in and of themselves, illegible. Many further processes are

required to bring these artefacts across the threshold of legibility. A striking illustration of this is given by the fact that when techniques for genetic ‘fingerprinting’ of cells were developed in the late 1960s, many cell lines that had been in circulation for years were found to be completely contaminated: ‘Monkey cells turned out to be human cells; human cells were shown to be mouse cells’ (Masters, 2002: 317).

There is, however, a clearly identifiable moment during the whole complex sequencing process at which the manipulated strands of bodily material become medium-indifferent. Once the colour-tagged fragments of copied DNA, still consisting of physical traces of bodily stuff, have moved across the electrophoresis gel and been sorted into bands, this results in a surface that is able to be photographed or broadcast or otherwise recorded any number of times and transferred across different media without any loss of meaning. The manipulations that depend upon the three-dimensional specificity of the molecular structure are at an end, and the work that remains only involves analysing the resulting two-dimensional traces that that structure has inscribed across a surface. The final product of this last stage of analysis is a very long string of letters.

At the most basic level, a string of As Cs Ts and Gs can be read as a description of the molecular structure of a strand of DNA, but this would be of little interest to us if we did not believe that the structure of DNA could, for its part, tell us something about the phenotype of the organism from which it was taken. It turns out, of course, that ‘reading’ DNA sequences is not nearly as simple as once hoped. For example, it is now estimated that only about 2 per cent of the human genome actually codes for amino acid sequences to make protein. Of that 2 per cent, many of the genes that code for proteins turn out to be split up across different stretches of the genome into short sections separated by long stretches of non-coding DNA. These split-up bits can be spliced together in different ways, resulting in different proteins, which means that in certain organisms potentially hundreds of different ‘readings’ are possible of one sequence.

The context-dependency of DNA does not end there. The question of what protein to make at what time is dependent upon the complex regulatory dynamics of the cell as a whole and not just the gene itself. Moreover, gene effects often depend on what other genes are present, so the genome has to be understood as a whole and not just a string of units each with a determinate outcome. Environmental context also determines outcome for most genetic effects: the genes that affect height, to take a familiar example, are dependent upon nutritional factors for how they are expressed in the adult organism.

The string of letters that make up a DNA sequence contains unambiguous information about the chemical structure of the molecule. This is in sharp contrast to the ambiguous, context-dependent, indeterminate, irreducibly complex relationship between that string of letters and the phenotype of the organism from which it was taken. This ambiguity is often cited—correctly in our view—as evidence against the view that DNA is *inherently* ‘textual’ or ‘informational’ in nature. A DNA sequence is but one of the many kinds of information that human tissues contain. Like all of these kinds of information, it has to be extracted using a variety of techniques. It can only be said to be textual in nature once it is actually a text—that is, once it has been rendered into a string of letters.

We would like to argue, however, that there are quite *practical* reasons for regarding DNA sequences as a special case of information extraction. The exceptional quality of DNA inheres in the relationship between the extracted information and its interpretation.

Like a DNA sequence, a photograph of tree-rings tells us something about the structure of a part of the natural world from which, given the right understanding of relations of cause and effect, we can deduce various further bits of knowledge. The photograph of the tree-rings tells us how old the tree was, and perhaps something about the length and intensity of the summers that it lived through. Unlike a DNA sequence, there seems to be a limited amount of information that can be gleaned from this resource. The very act of selecting the pattern of light and dark bands that run through the trunk of the tree as the relevant bit of information-bearing structure from which to make a text imposes a limit on what can be known about the tree from the replicable, two-dimensional artefact that has been created. The DNA sequence by contrast, for all the difficulties attendant upon its interpretation, is an informational resource of stunning richness and intricacy. Just on its own it can already tell us much about the organism from which it was taken. If it is embedded in a database allowing for comparative work, and linked to other kinds of information such as disease histories, it is a text that is constantly susceptible to clearer readings (although many of those will take the form of probabilities rather than certainties), whose potential applications are almost infinite.

We would like, in other words, to argue for what philosopher of biology Tim Lewens has called ‘exceptionalism by degree’. Lewens proposes that:

There is no important difference between letting an insurer know that one has a gene that disposes one to cancer and letting an insurer know that one was brought up in Cornwall where a granite rich environment also disposes one to cancer through radiation.

But he goes on to caution:

There are, however, reasons to be especially cautious of the information about us that is contained in our genome, primarily because of its ease of capture from a cell, and because of the availability of cells. There is no environmental analogue to the cheek swab followed by the complete sequencing of an individual’s genome: there is no simple set of actions that can capture the totality of information regarding one’s environmental developmental resources. Perhaps school records will give an indication of what one was taught growing up, and a parent’s supermarket receipts might give an indication of what the growing child ate. Yet one’s environment simply cannot be sequenced in the same way, although information can be gathered about it. (Lewens, 2002: 214)

Lewens’s vision of what it might mean to ‘sequence’ the environment captures something of the richness of information contained in the order of bases in DNA.

In our discussion of tissue blocks and slides we suggested that tissue samples rather than digital photographs of tissue slides had to be retained in hospitals because microscopic examination does not actually exhaust the range of readings to which a slide may be subject. The possession of the thing itself, and indeed of the block from which it was sliced, provides for unforeseen or unprecedented manipulations to be carried out, should the need arise. Partly because of the very difficulties of interpreting the texts of DNA sequences, these strings of letters have the same almost inexhaustible capacity to lend themselves to unanticipated uses and manipulations.

Nucleotide sequences describe a structural feature of the body embedded in such intricate relations of cause and effect that these texts have much of the evidentiary value and depth of information of physical samples. The common characterization of DNA as a text may partly reside in this very quality of the molecule: the functional significance of infinitesimally tiny differences in the structure of a particular organism's DNA is what leads us to engage in a process of amplifying the material through replicating it billions of times and then breaking it down into billions of fragments in order to produce a detailed description unique to that particular organism.

The DNA archive is data at its most raw. Not only can we still not read these texts with any fluency, it is even impossible to know the extent of what we might learn were we entirely literate in the language of nucleotide order. Estimates vary wildly from the determinists' belief that we will discover genes for complex behaviours like criminality and sexual orientation to the extreme sceptics who think that the predictive insights afforded by genomic sequences will be more or less restricted to single-gene diseases like Huntingdon's.

Rendering information in a textual form often represents the end stage of information extraction. The salient features of a bit of the natural world have been selected and made visible, and the rest has been discarded, resulting in a replicable, legible artefact. DNA sequencing technology divests human tissue of its materiality by a process of selecting the nucleotide order along the length of the DNA molecule as the salient characteristic of the material and rendering this information in a textual form, but this is only the very first step in a much larger process of information extraction. The cause-and-effect mechanisms that are of interest are far upstream from the raw data of the sequence.

We are thus confronted with a rather different problem from that discussed in the last section. We concluded above with the thought that some of the relevant differences between material and textual resources are that the former are unpredictable, replete with infinite informational potential, but physically finite and liable to be destroyed in the course of being investigated, whereas the latter are infinitely transmissible but informationally finite. In the case of DNA archives we have a resource that seems to be both physically and informationally infinite, replicable any number of times without being used up, but also replete with potential for different kinds of analysis.

We began this article with a consideration of whether tissue blocks and slides archived as part of the medical record should be treated as material or informational resources. The simplicity of the technology involved and the apparent straightforwardness of the problem allowed us to examine closely and carefully the relationship between objects, texts and information, analysing why and how different components of the medical record should be legislated differently. We concluded that the relevant criterion for an informational, as opposed to material, resource was the characteristic of 'medium-indifference'. We then discussed how and why this distinction might matter in law and ethics.

Having made these distinctions, we then turned to the more complicated case of the DNA archive. The distinctions and definitions proposed in the first half of the article were then deployed to slightly different ends, put to work to help clarify the pragmatic (rather than the metaphysical) significance of the DNA sequence's special status in, among other things, the 2004 Human Tissue Act. It is one of the ironies of our 'Information Age'

that the very word that it is supposed to define it has accrued so many different meanings as to be completely imprecise. We hope to have made a preliminary step towards clarifying one small area of the confusion that has resulted.

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