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Understanding Innovative Health Technologies



Introduction

This is a book about one of the most significant social transformations of recent times. It is a book that explores fundamental changes in the way we understand and manage our health and our bodies, and how this understanding has been shaped by, and given expression through, developments in medical and related technologies. But it is also a book that is built on a strong sociological scepticism about how we should read these changes: we should not presume that they are necessarily progressive, nor always of value or utility. Nor should we expect that the technological promise of fields such as genetics and informatics will be made equally available to all, and when so, always happily embraced. Sociological scepticism also recognises that although many technological changes have global reach – at least in those modern societies that can afford them – they will be subject to vastly different local interpretations and uses.

A sociological perspective argues that these technologies and the techniques, models and assumptions on which they are based, are *given* meaning through the way they are tied into *other technologies and social practices*. This is true whether they appear in the most mundane (such as the stethoscope) or the most exotic (say the MRI scanner) of forms. The meaning of health technologies will also vary in different settings (from the clinic, to the home, to the Internet), and vary in the way they shape diverse notions of ‘health’ found within and between cultures. In this sense, technologies (not only of health but all fields) are best understood as an expression of, and thereby always expressed through, social relationships. It is for this reason that technologies have been described by Haraway (1997, p. 11) as forms

of ‘materialized figuration’, inasmuch as they bring together (or configure) material, people and social meanings or as ‘congealed social relations’ (Grint and Woolgar, 1996). Technologies perform, or ‘work’ within the context of, as well as through, such relationships.

The book is also about how new technologies are engaged with at an everyday level where these relationships are played out, in, for example, the hospital setting, primary practice and the home. What do encounters with technology mean for the health practitioner and patient, and indeed for those who surround them, such as a patient’s carers and wider kin? New techniques – such as a genetic test – may, for example, provide greater precision in regard to the diagnosis of disease susceptibility, but may have little to say about the likely experience of ill-health or actual degree of discomfort a person – or their family – might expect to have some time in the future. Will this reassure or create new anxieties for those involved? In this sense, medical technologies are two-sided: they provide new, more detailed, sources of information about our illnesses but at the same time new forms of uncertainty and risk. These relate not only simply to our understanding of the illness but also to the expectations that inform and guide the social relationships *through which* we define and manage it. If technologies are congealed social relationships, those that disrupt existing relationships can be especially problematic.

New health technologies not only disrupt relationships we have with other people, they can also redefine our relationship towards our own body and our sense of being well or ill, our sense of control over our body and its parts. As I have argued elsewhere (Webster, 2002, p. 446) these technologies can reinvent the boundaries of the body in space and time by reducing them to their basic biochemical or anatomical constituents and reconstructing them in novel ways. We shall see, for example, how this occurs in fields such as stem cells or digital telemedicine.

New fields of medicine might be expected to have this effect, but even when technologies are commonplace and everyday – such as the ubiquitous antenatal screening techniques used to test for fetal abnormality – this does not mean that their diagnostic or therapeutic value will remain stable: over time, the value of technologies changes, perhaps because of better ways of getting patient information, or delivering the treatment they provide, or through changing social expectations about treatment (particularly evident when patient advocacy groups seek access to experimental drugs). Moreover, the ‘value’ of medical techniques, devices or therapeutics (such as new drugs) is typically subjected to national (and international) evaluation,

regulation and monitoring. These evaluations are anchored in wider social and political cultures, explaining the global diversity one sees in the regulation of fields such as stem cells research. This points more generally to ethical debate over new technologies and the very different perspectives that can be found between and within countries.

Apart from asking about the meaning, value, regulation and ethical implications of health technologies, a sociological perspective is also interested in the processes through which new health technologies are introduced in the first place, and what factors have shaped their introduction. Health and its definition depend not merely on a person's sense of well-being, but on powerful professional, commercial and institutional interests that capture health in order to define, control, exploit or deliver 'it'. Health technologies in this sense are developed as part of a much wider innovation system and indeed may well emerge from fields that have nothing directly to do with the conventional clinical management of health. This is the case, for example, in regard to the widespread introduction into health systems of information and communication technologies (ICTs) developed elsewhere and now deployed for information management purposes and treatment (as the growth of telehealthcare illustrates). In 2005, for example, the United Kingdom government established its national programme for information technology in the health services, 'Connecting for Health', that will link general practitioners, hospitals and pharmacists and allow the electronic transfer of patient records. In other words, technologies spill across fields and markets through the complex network of relations that mobilise them. This means that products on health share many features of products used elsewhere, while the convergence of high-tech engineering and information systems – such as the intersection between bioinformatics and nanotechnology – blurs the boundaries of what is to be regarded *exclusively* as a 'health' technology.

While these national (and indeed international) medical and commercial interests set the health agenda for many of us, it is also the case that as *consumers* of health, people capture health innovations for their own personal use, especially in fee-based health markets such as the United States, a model increasingly adopted across Europe and Pacific Rim countries. Online health advice and products (such as pharmaceutical drugs) as well as techniques (such as diagnostic tests), have helped to drive the expansion of consumer-led health. The Internet also allows people to subvert and circumvent national systems of regulation and differences in state provision for health. As we shall see later in the book, many people exploit this virtual world of health,

whose territory extends way beyond that which is subject to the clinical gaze. And, of course, the body itself has become a site of consumption, especially through the huge market in body modification through ‘cosmetic surgery’ and what Conrad and Potter (2004) have usefully termed ‘biomedical enhancement’ that includes ‘drugs, surgery and other medical interventions aimed at improving mind, body or performance’ (p. 185). They also advise against our assuming that there is a clear divide between medical ‘treatment’ and these interventions, inasmuch as we might assume that the first relates to health need while the second to lifestyle choices. They point out that the boundaries between these two are ‘movable . . . and highly contested’ (p. 186).

While the Internet and consumer markets open up and increase the demand for more diverse health goods and services, it is nevertheless the case that there is a strong relationship between the profile of disease in modernity and the clinical technologies that are seen as most important and effective in managing disease. In this sense, the technologies mentioned above do not appear randomly: while it is certainly the case that some technologies appear in a rather ad hoc fashion, championed by individual clinicians, there is a clear structuring of health care, medical research and commercial investment around specific areas.

For example, US physicians recently identified the top five innovations according to their *relative* importance in the treatment of patients’ disorders: these were MRI/CTC scanning, ACE inhibitors, Balloon angioplasty, the Statin drugs and Mammography (Fuchs and Sox, 2001). All five are related to the most common chronic and/or high mortality diseases of advanced consumer societies – cardiovascular disorders (angioplasty and statins), cancer (MRI, CTC and mammography), and hypertension (ACE inhibitors). In turn, in those countries where it is the state that acts as the main procurer and provider of care, there is a growing trend towards procurement according to certain standards (technical and clinical), targets and cost in these and other areas. This may constrain the adoption of medical innovation (as has been claimed, for example, in recent UK-based reports (e.g. Wanless, 2002)). In market-based systems, such as the United States, new technologies have been much more quickly taken up in part because professional care is fee-based and specialist, and where patients are ‘clients’ with private health insurance, a physician competes with others in part through what state-of-the-art medicine they have on offer. Moreover, as insurance cover meets the cost of technical services (such as ultrasound scans during pregnancy)

hospitals are more likely to encourage patients to have more scans, simply because they will provide a useful income stream for the hospital itself.

Whether we are speaking about socialised or privatised forms of care, similar patterns of illness and disease can be found in all affluent societies. The disease areas noted above are, of course, closely related to the ageing process and a general decline in bodily well-being, and universally mean that a large proportion of health resources are devoted to older members of the population. Health care demands are also high at the other end of the life course, where ante- and peri-natal care up to the first few months of a child's life account for a disproportionately large investment in health technologies through screening, diagnostics, testing, life support and so on. Increasingly, of course, illnesses of affluence and over-consumption – notably obesity – are growing at an alarming pace: in many countries almost 50 per cent of the population is classified as being overweight or obese (OECD, 2004). Whether it is at either end of the life-course or between, medical intervention to manage morbidity and/or to save life is always high-cost in terms of both the labour and technologies it demands (such as in intensive care units).

This raises the question of resourcing for health interventions and who pays for it: the consumer or the state. In most socialised health care systems, such as the United Kingdom and Australia or mixed systems such as Sweden or the Netherlands, the state often sets a cut-off point or threshold beyond which the burden of ill-health or disease should be met by the private individual rather than through state provision through national taxation. In addition, most advanced states encourage their citizens to buy into private health insurance: for example, although Australia provides universal access to health care regardless of their ability to pay, almost 45 per cent of its population also have private health insurance (Hilless and Healy, 2001). The demographic shift towards a greater number of older people in the population as a whole will increase this trend towards private insurance. Increasingly, governments are encouraging patients, and their carers, to become more responsible for their own health, aided by devices that can be used by patients themselves in their own homes. This is especially true for the management of chronic illness, a potentially huge drain on the state. Self-care is, of course, likely to be politically framed in terms of a discourse of patient 'empowerment' rather than one of saving money. These trends towards self-administered medicine have implications for the traditional relationship between

doctor and patient, as we shall see later in the book when we examine what I call ‘the new sick role’.

This brief introduction has sketched out some of the main areas of interest that are to be explored later on and that indicate the complexity that is health technology today. But how far, we can ask, is this complexity significantly different from medical technologies of the past? That is, are we seeing today some sort of qualitative shift in their character and use, the way we make sense of them, or is there much that they have in common with the past? It is to this question that we can now turn.

New technologies, new health?

It is useful, first, to say something about what many regard as innovative health technologies. This cannot be presented as a straightforward list, for this would be to presume in advance some *intrinsic* quality of novelty that can be identified in some, but not other technologies. Instead, we need to understand what it is that people perceive as new about these developments and why.

One way of identifying what might be regarded as good candidates for innovative technology is to look at those areas receiving disproportionately large levels of public and private funding upstream, in the research labs of corporations and universities, or those appearing in documents of a health policy world that spends all its time scanning the ‘horizon’ for ‘disruptive’ technologies. We are also likely to find these same technologies populating the pages of science journals, the press, TV and the Web. Here we can find a range of developments that appear time and again; the more common of these are:

- Genetics-related developments (especially the advent of new technologies for genetic diagnosis, testing and screening; gene therapy; pharmacogenetics and pharmacogenomics; and neutrigenomics);
- informatics-based systems used for monitoring the individual – such as biosensors or telecare; telemedicine deployed for diagnostic (through imaging/ultrasound) and therapeutic purposes; and information systems used to manage clinical data about patients;
- tissue-related, such as tissue engineering and (adult or embryonic) stem cells research and therapy;
- Let us look at each of these in turn, focussing in particular on why each of them is regarded as transformative, at least according to those that develop them and bring them into the health care system.

Genetics-related developments

Traditionally, medical genetics has been mainly focused on the inheritability of single gene disorders related to a mutation in a person's DNA that is passed from one generation to the next. There are different degrees of risk of inheriting such disorders according to whether the genetic mutation is 'dominant' (such as in Huntington's disease where if you inherit the genetic disorder the disease will appear) or 'recessive' (as in cystic fibrosis or sickle cell anaemia) where you may simply be a 'carrier' of the mutation without it being 'expressed' as – an ultimately fatal – illness; here you need the defective gene from both your parents to succumb to the disease. A third form of genetically inherited disorder is known as X-linked and refers to single gene mutations (related to muscular dystrophy, for example) found only in the sons of women who carry the mutation.

The determination of these types of disorder is based as much on taking a thorough family history as it is on genetic testing, and the latter has been used for many decades in medicine. These tests are used to determine the likelihood of a disease and its relative severity (in part derived from the so-called 'penetrance' of the genetic mutation). In the particular area of reproductive genetics, techniques used include using microscopy simply to see whether there are additional chromosomes (as in Down's syndrome), testing a mother's blood chemistry for an over-expression of enzymes produced by the mutation, or removing by amniocentesis some of the amniotic fluid carrying foetal cells and testing them in the lab for markers linked to mutations. Information on family history is especially important in later onset diseases such as breast cancer.

How, then, might developments in 'the new genetics' differ from these conventional genetic techniques? The areas noted above – new diagnostics/testing/screening, gene therapy, pharmacogenetics/genomics and neutrigenomics – all depend for their novelty and applicability on the results of the Human Genome Project, the sequencing of the long chains of deoxyribonucleic acid (DNA) that make up the human genome. This mapping 'project' was begun in 1990 and was completed in draft form in July 2000, and a more developed version again in 2004. The more recent map is, perhaps ironically, presented less as a blueprint of the genome from which it would be possible to read off genetic mutation and its effect on the body, and more as a useful reference point through which gene hunting is made possible. Even so, it was this map, more than anything else, that has inspired claims that new genetic information would transform medicine.

Genetics would no longer be primarily reserved to working on diagnosing single gene (or monogenetic) disorders: instead *multifactorial* disease would become the new target, whereby illnesses and diseases caused by gene–gene or gene–environment interaction would now be understood, a move away from a focus on managing disease to preventing it arising in the first place. Where the disease already existed, this could be treated through gene therapy, modifying a person’s DNA such that they would no longer produce the mutations that made them chronically or fatally ill.

The sub-field of pharmacogenetics, which goes back many years, has now been transformed by the HGP, primarily because it has become possible to identify those genotypes that are more, or less, responsive to drugs. In theory, it heralds the era of so-called personalised medicine.

More recently, food and genetics have been directly linked in the field of nutrigenomics, that applies genomics to diet: primarily it seeks to understand the relationship between a person’s genome and how a specific diet might help mitigate or pre-empt the onset of genetic disease (Kaput and Rodriguez, 2004). It also examines the genetic basis of food organisms themselves in order to produce ‘functional’ food products that have a beneficial effect on health. This is attracting major investment in the commercial sector and the emergence of hybrid food/drug companies keen to cash in on high value-added (i.e. profitable) goods in a health-conscious consumer market.

These developments associated with contemporary genetics have been said to mark a sea-change or ‘revolution’ (European Parliament, 2001) in medicine. There are three changes which receive most attention:

1. *The diagnosis and treatment of both single and multifactorial disease.* Single gene disorders, such as Huntingtons, have been impossible to treat other than in a palliative sense: the onset of the disease is inevitable, such that, as McEwan (2005) so elegantly and terrifyingly notes, ‘the brilliant machinery of being is undone by the tiniest of faulty cogs, the insidious whisper of ruin, a single bad idea lodged in every cell’ (p. 94).

Gene therapy could, drawing on genomic information, develop techniques that would make good these single gene disorders. At the same time, it is suggested that medicine will be increasingly centred around tests for late-onset multifactorial diseases, those diseases individuals might get in the future. The medical practice this *predictive* testing generates, therefore, will not so much focus on concrete complaints and pains, but *risk-assessments* of diseases to which individuals (including the

pre-born) are susceptible and which they might only obtain later on in life. Genetics research is now being related to a wide range of pathologies including cancer, diabetes, coronary heart disease and mental illness. Sociologically, however, this move towards risk assessment rather than the management of actual symptoms can generate new forms of uncertainty for both the ‘patient-to-be’ as well as clinicians (Bharadwaj et al., 2006). It could also be hugely expensive for socialised health care systems, such as that found in the United Kingdom, if risk assessment were to be based on the DNA profiling of all 600,000 babies born each year, in order to be used later in life to confirm a patient’s genetic risk diagnosis (HGC, 2005).

2. *The development of target disorders.* Key to this is a move in medicine away from looking at clinical manifestations (the phenotype) of illness and disease to the underlying genetic causes of diseases. Many diseases share some molecular features at the genetic level. As a result, this might lead to the redefining of disease categories once perceived as similar or quite distinct on the basis of clinical symptoms. From a sociological perspective, this re-classification of disease could have major implications for existing professional boundaries and clinical practice, while creating ever-greater pressure towards a reductive geneticisation of illness and indeed of social problems more generally (Lippman, 1991; Hedgecoe, 2004). How far this type of tidy reductionism is sustainable is open to question, however, not least because within bioscience itself there is an increased recognition of the instability and complexity of genetic information.

3. *The targeting of drug-based treatments.* The possibility of targeted drug treatments is related to two areas of pharmaceutical research, namely, pharmacogenomics, how knowledge of the genetic composition of diseases themselves, such as cancer, can enable the development of a particular drug to target the mutating gene; and pharmacogenetics, a more precise understanding of how a person’s particular genetic make-up (or ‘genotype’) affects the response they make to a specific drug (Webster et al., 2006). Some common drugs, such as warfarin, have a very narrow ‘therapeutic index’, which means that the most beneficial and non-toxic effects of the drug are limited to those patients with a particular genotype. So pharmacogenetics could, if fully realised, not only reduce unwanted side effects for patients but also lead to the more effective (therapeutic) use of drugs. Drugs are of course commercial products subject to international regulation: so we need to ask how might the advent of pharmacogenetics change the way in which corporations develop new drugs and regulators oversee the safety and efficacy of drugs?

Informatics-based system and e-health

Information systems are a key part of all social systems and are central to the reproduction of social order, forms of control and the exercise of power. This is true in health as it is in politics, education, the media and so on. The role of information in health and medicine today has to be seen in the changing context within which the information system more broadly has changed, especially over the past 30 years or so. Just as the HGP has been seen to transform genetics, so the ‘information revolution’ of the 1970s and beyond has been said to radically alter the meaning, scope and purposes of data, its flow, management and complexity (see e.g. Forester, 1984; Rozsak, 1986; Webster, 1995). This in turn has had a major effect on the ways in which health information is classified, sought, and deployed within and outside the clinical setting.

Late-modern societies are characterised by impersonal interaction, individualisation (Beck, 1992) and the disembedding of social relations (Giddens, 1990; Lash and Featherstone, 2002), across spatially extensive boundaries and networks (Castells, 1996) through a global communications media, driven by the World Wide Web. These changes have depended on key shifts in the ways in which information technologies (IT) are configured and the capacity that they have to manage information itself. Miles (2002) has argued that in the 1970s IT facilities were few, large (mainframes), and detached from one another. Subsequently, the 1980s saw the growth of IT devices (PCs), of many (and much smaller) sizes, with limited (two-way) communication between them being the norm, while the market was opened up through the deregulation of telecommunications and the arrival of satellite television. The 1990s saw the rapid growth of the Internet and Web as ‘information superhighways’, with technical links between the Web, email and G3 mobile phone systems. In the twenty-first century IT is now regarded as being embedded within the physical and virtual environment: wherever we turn we find IT systems at work, often invisibly so. This is what is meant by ‘ubiquitous computing’ deploying ‘ambient intelligence’ (Ducatel, 2000). Information of all kinds is handled as digital data: this makes it easier to transport information from one device to another – a move from centralised information processing to mobile and interoperable processing systems.

These developments have been particularly evident and exploited in some core social institutions within the ‘virtual’ or ‘e-society’ (Woolgar, 2002) and expressed in e-government, e-learning, e-commerce, and, of relevance here, *e-health*. E-health refers to a mix of digital technologies

whose function is to diagnose, monitor, store and relay information about health, the patient, and the huge volume of management data-flows that characterise national health systems today. They reflect a time of audit, standardisation, technocracy and ambitions towards more efficient systems for managing health resources. As I have argued elsewhere (Webster, 2002, p. 450), the contemporary medical world is becoming increasingly 'informaticised'.

These digital technologies are networked, mobile and extensive. We can see a rapid expansion of embedded systems incorporated into bodies themselves as with biosensors, devices that convert a biological response into a digital electrical signal which can then be tracked remotely and logged by a central server monitoring a person's condition – such as their blood pressure. As Virilio (1998) remarks, we 'have to cope with technology inhabiting us. "Smart pills" are developed which are able to transmit information on nerve functions or blood flows to distant monitoring facilities' (p. 53). Ultimately, so extensive will our technological embodiment be that Virilio believes we will become 'citizen-terminals' where we are 'decked out to the eyeballs with interactive prostheses' (p. 20).

At the same time, the training of new medics need no longer solely rely on physical bodies – dead or alive. The physical link between the person, body and health is challenged by the arrival of cybernetic medicine where supercomputers are deployed to produce models of '*in silico*' organs, organ systems and eventually the 'Virtual Human'. Medics today are being trained online and in the computer suite through software programmes that generate virtual bodies rather than being required to learn their craft using cadavers or volunteers.

E-health is also found within buildings, such as 'smart homes' for the elderly or the chronically ill, including the monitoring and remote imaging systems used in telecare and telemedicine. Clinical data (inscribed within an Electronic Patient Record) is itself being incorporated into massive information handling systems such as the United Kingdom's 'Connecting for Health' programme, or the Australian 'Health-Connect' initiative (both rolled out in 2005). The United Kingdom programme is the most ambitious system being introduced worldwide and is designed to give 30,000 British doctors access to patient records, that will (it is hoped) by 2008, support five billion transactions a year, including online decision-support.

Beyond the formal health system, more and more people, through increased domestic access to the Internet are using the Web as a source of health care information. As Fox et al. (2002, p. 4) note, more people go on line in the United States to secure health information than

do visit their physician. Nettleton (2004) describes the emergence of 'e-escaped medicine', suggesting the formation of a new health information landscape occupied by virtual 'wellness managers', 'expert patients' surfing the net, health seekers in chat rooms and so on, signalling at the same time a move away from, an escape from the domain of orthodox medicine itself. As she says:

Medical knowledge is therefore no longer exclusive to the medical academy and the formal medical text. It has 'escaped' into the networks of contemporary info-scapes where it can be accessed, assessed and re-appropriated. Rather than being concealed within the institutional domains of medicine, knowledges of the biophysical body (hitherto medicine's most sacred object) seep out into cyberspace. (p. 674)

These developments, as with any disruptive technology, generate not only new types of social relationships – to our bodies, to and between medics, to the state – but also new risks and threats. For example, telehealthcare can be said to have contradictory effects: on the one hand it is deployed in order to enhance patients' autonomy (e.g. by allowing them to remain at home); on the other hand for it to work patients must be compliant to be remotely 'activated' through a distributed information system infrastructure (Mort et al., 2003). Patient carers are caught up in this process at the same time and required to carry an ever-increasing burden of responsibility for health. Or again, the volume and flow of information creates new risks with regard to an individual's rights to privacy and concerns over who has authorised access to patient information. This is especially so in the United States, where privacy laws are less strict than they are in the European Union.

Whatever the risks and opportunities afforded by informatics, its transformative potential seems clear, and indeed it gains greater momentum through its tie-in with those developments in genetics noted above. In fact, the relationship between the genetic code of DNA and the digital code of software is critical to the future of biomedical science. As Hine (1998) has observed: 'without [informatics] all the accumulated knowledge [related to genomic research] would be a disorganised heap as unreadable as the genome itself' (p. 42).

The third, and final, area we can consider that is seen to herald a major shift in the configuring of health and medicine concerns the field of tissue engineering and stem cells research. Hine's reference to a 'disorganised heap' might well describe the problems faced by

biomedical scientists trying to understand, stabilise and use ‘wet biology’: tissues collapse, cells do things differently than expected, and the media used to grow them may well contaminate them or produce false readings. So there is considerable effort spent in trying to sort out, classify, standardise and organise this biological micro-world, whose main features are sketched out below.

Tissue-related biomedicine

Most bioscientists working in the tissue engineering field use the term ‘regenerative medicine’ to capture its hopes and aspirations: that is, they hope to engineer the properties of tissue and cells so that they might be introduced into a patient in order to regenerate damaged or non-functional tissue – such as bone, cartilage, blood cells and so on. In many areas, this research combines biological tissue with synthetic materials. This has been used, for example, to create new tissue used for the treatment of ulceration and skin lesions often associated with diabetes, or for the treatment of serious burns, or the repair of bone fractures (Faulkner et al., 2003).

Stem cell research has two main wings to it: work on adult stem cells which stretches back more than 40 years, and the much more recent (and socially contentious) embryonic stem cell research. The potential advantages of stem cell technologies include the potential to cure currently incurable conditions, such as Parkinson’s disease (carrying McEwan’s ‘insidious whisper’), to mend damaged organs such as the heart and spine, and to provide an important new advance in drug toxicity testing, based on human models rather than animal models that have in the past proved unreliable.

Adult stem cells (alternatively known as ‘somatic stem cells’) serve to reproduce through maintenance and repair the specific tissue/organ within which they are found. If these cells can be isolated and extracted from oneself (autologous) or other people (allogenic) they can be used therapeutically to treat disease. For example, research in bioscience labs is being undertaken to identify those cells that function as heart muscle that could then be introduced into a patient suffering from chronic heart disease to repair damaged tissue. Such cells, it might be suggested, offer the heady promise of replacing self with self.

An adult stem cell’s functionality is primarily determined and limited to that part of the biological system within which it is located, though recent research suggests that these cells might be coaxed into differentiating to form other cells. It is this capacity – this potential – that is the defining characteristic of embryonic stem cells. Unlike somatic cells

these are special kinds of cells that have the unique capacity to renew themselves indefinitely and to give rise to specialised cell types. While adult cells perform a specific function, an embryonic stem cell remains uncommitted until it receives a signal to develop into a specialised cell. These stem cells vary in their properties. At the earliest stages of development of a foetus, up to about eight cells, all the cells are ‘totipotent’ (meaning they can develop into every type of cell needed for human development, including extra-embryonic tissues [that is the placenta and umbilical cord]). Once the blastocyst stage is reached (50–100 cells) embryonic stem cells (ES cells) can be derived which are said to be ‘pluripotent’.

This class of stem cell, which is not only found in embryos at the early stage of development, but also in some foetal tissue, has the potential to develop into almost any of the 200 or so known cell types, although not into extra-embryonic tissues. Embryonic stem cells come from donated ‘spare’ embryos created as a result of *in vitro* fertilisation (IVF) programmes. Clinics offer IVF services to couples who have been unable to conceive, the clinical technique depending on the production of ‘supernumerary’ or surplus eggs, some of which can be taken for experimental purposes. Another type of stem cell, human embryonic germ cells, are derived from medically terminated pregnancies; these stem cells which come from the foetus in a later stage of its early development are not known to be pluripotent.

The first reported isolation and growth of pluripotent stem cells from early human embryos was made in 1998. Since then, the field has grown rapidly, though it has yet to deliver clinically therapeutic results. While adult stem cells are derived from mature tissue, here biomedical science might be said to be sourcing tissues from ‘the very margins of (pre-) human life’ (Waldby, 2002, p. 313). It is the clinical possibilities associated with ES cells that can be seen to constitute a radical break with existing biomedical science. The cloning of these cells and their cell lines in contemporary research breaks the direct physical relationship between bodies, tissue and its subsequent use: this contrasts with conventional transplantation for, in that case, organs donated from one person are used by one other person to sustain their life (as in heart, lung or kidney transplants). In contrast, stem cell donation derived from IVF treatment has no single recipient. Cell lines can be cloned indefinitely and be encouraged to differentiate into one form of tissue rather than another, and introduced in many different patients. The nearest medicine gets to this at present is in blood donation, where those of a particular blood group will be

able to use blood of the same group from someone they have never met. But this is only ever blood: stem cell differentiation allows for the very possibility of creating such blood – or in theory any other ‘tissue’ – in the petri dish.

If this is to be achieved, however, the cells need to be stored and maintained, their quality ensured, and the biological and clinical standards that they must meet set down very precisely. This is the job of the new institutions known as tissue or stem cell banks found across the world today, that act as repositories for the new ES cell lines developed in bioscience labs in Australia, India, the United Kingdom, United States and so on. The procurement and banking of human tissues has become a major logistical task, surrounded by extensive regulatory and ethical provisions and codes. These new institutional structures are themselves indicative of the novelty of ES research.

We have seen, then, how the new genetics, informatics and tissue engineering/ES research disrupt existing and open new clinical possibilities while at the same time creating new socio-technical relationships. As such they are important candidates for sociological scrutiny. In each case, however, we have noted that they do not drop from some bioscience lab in the sky but are based on earlier scientific and technical developments already found ‘on the ground’. So our questions as sociologists are less about the precise technical shifts they mark, important though these are, but more about the sense in which they are part of, and enabling conditions for, a transformation in the wider relationships between health, technology and society. What sort of questions might lie at the heart of such a sociological analysis?

Developing the sociological critique

There is a rich sociological literature exploring health, illness and, more recently, health technologies (ESRC, 2005) and their role in shaping the relationship between health practitioners and patients (e.g. Hanlon et al., 2004), the embodied sense of illness and disease (e.g. Flowers, 2001), the meaning and classification of disease itself (Kerr, 2005), and the wider professional and regulatory changes that characterise modern health care systems (e.g. May et al., 2004; Salter et al., 2004).

Prior to this more recent work on health technologies, there had been a much longer tradition in social theory that located health squarely within the wider structural and cultural dynamics of society.

Foucault (1975), for example, was interested in the ways in which knowledge, power and social control was produced and reproduced through the clinic: the clinical ‘gaze’ determines the basis on which identities are defined and classified, so sorting the mad from the sane, and the medium through which people become an object for scientific ‘subjectification’. Without such discourses, these classifications and the divisions between normality and abnormality they create would not have existed: madness is a discursive product. More recent work exemplifies the play of classification processes: for example, Prior et al. (2002) show how those presenting with breast cancer fall on one, or another side of the threshold for treatment and clinical monitoring. Such classification reflects not only the conventions of scientific expertise but also the ‘political calculus’ that determines the rationing of health resources in the field of oncology. Similarly, Lippman (1992) has explored the way in which illness has become re-classified in terms of contemporary genetics discourse. Some can ask then whether the new technologies produce different types or forms of ‘political calculus’, as the relation between classification, disease risk and its management change the structuring of health care delivery?

Sociologists have also been interested in the ways in which patterns of social inequality are reflected in patterns of disease and the availability of health care. Bury (1997), Bartley (2003) and Stacey (1988) for example have examined the distribution of morbidity and mortality against social class, gender and the allocation of health resources. How, we might ask are these structural patterns of health mediated by the new technologies sketched out above: will, for example, the introduction of e-health exacerbate or ameliorate access to health care and advice?

In parallel, and perhaps not surprisingly, work in the field of the sociology of science and especially science and technology studies (STS) has become increasingly interested in examining the role of technologies in (re-)defining the meaning of health, disease and the role of the clinic (as in Casper and Berg, 1995; Berg and Mol, 1998; May and Ellis, 2001; Brown and Webster, 2004). More historical studies in this tradition remark too on the move away from an interest in the patient *per se* to disease and the technologies that can control it, or, in Pickstone’s (2000) words from ‘biographical’ to ‘techno-medicine’. Others observe how this shift has been driven by private corporations keen to exploit innovative technologies in the biomedical market, especially in the United States. This defines the move away from a public health framework for medical provision, to one which

has become increasingly obsessed with ‘miracle technology’ – the creeping fetishisation of technology, hardware and gadgetry (Blume, 1997). Pharmaceutical and wider health care industries whose products populate the high street, the clinic and the home, operate in global and local markets, and engage with government and regulatory actors in such a way as to ensure their goods and devices are usually well-received (Abraham and Lawton Smith, 2002).

One important feature of ‘technomedicine’ is its capacity to keep people alive when they might otherwise have died, most obviously illustrated in the life-sustaining power of the intensive care unit (Lock, 2002). Less dramatically, technomedicine also ensures that there are more chronically sick than ever before, as drugs and devices keep the body going. Bury (2000) has noted how the demographic shift towards a greater number of older people in the population simply magnifies this ‘problem’, such that the focus of many in medicine has shifted from ‘treatment and cure’ to ‘management and care’ (p. 267). Technology ejects people from acute and fatal disorders into long-lived chronic illness.

In such circumstances, the meaning of someone’s illness and its place in defining their personal identity becomes key: chronic illness is likely to form a key component of a personal biography or life story. Indeed, the focus on personal illness ‘narratives’ has been a key feature of much medical sociology. In the past – and still today – narratives have been anchored in the expectations associated with the sick role and the way medicine, having identified the causes of one’s problem, provides a cure or treatment for it. Today this curative model is accompanied by a growing medical discourse and patient narrative centred on risk: instead of identifying symptoms and their treatment, doctors are increasingly identifying possible risks and creating a large number of the so-called worried well, those with no symptoms but who may succumb to illness in the future (Bharadwaj et al., 2006). How do these developments create new senses of illness and the body at the level of personal experience?

In light of the above, what then can we say provides the core issues that would inform a sociological critique of the relations between health, technology and society? Such a critique, I suggest, would explore and challenge the implications of medical technoscience with respect to:

- the socio-economic factors shaping innovation and how these affect the structuring of health care delivery;
- the patterns of inequality in morbidity and mortality;

- the public and private institutions that are investing huge amounts of political and economic capital in existing and novel areas such as genetics, informatics and tissue engineering fields;
- the regulation and control of new medical technologies;
- embodied knowledge about and experience of health and disease.

These are the main issues that underpin the rest of this book. Though they are directly and explicitly tied to debates surrounding technologies per se, they need to be understood as part of a wider range of structural and institutional changes characterising contemporary societies that are not restricted to the field of medicine and health. These include the growing individualisation of our lives, the changing relationship between lay and expert knowledge, the increasingly globalised contest over (health) rights and resources, and tensions between the political regulation and economic promotion of innovation by the state. Where possible, I will broaden the focus to include reference to these wider themes throughout the book.

Returning more specifically to medical innovation, I have argued elsewhere that we can see developments in technoscience in terms of three broad but related changes that have opened up clinical medicine to new influences and actors. These I have called the *socialisation of medical innovation*, the *socialisation of clinical diagnosis* and the *socialisation of clinical implementation* (Webster, 2002). The first refers to the ways in which lay people are enrolled as *active participants* in the development of new technologies from their very earliest stages of development. This is not simply as volunteers for clinical trials, but as users encountering health services and goods beyond the clinic. Health innovation is dependent on socially and spatially distributed and mobile systems that are less and less contained within the walls of a clinic. The ‘where’ of medical innovation becomes as important as the ‘what’ to which it refers precisely because the very rationale of the innovation is that it is – as Giddens (1991) might say – time-space distanced. And this distancing is given increasing impetus through the role of the state as procurer of medical innovation: it will seek to secure those new technologies and interventions that relocate care and its delivery to non-clinical settings.

The second change refers to the fracturing of the medical monopoly over the meaning of health and disease, especially through the arrival of what has been called a ‘new medical pluralism’ (Cant and Sharma, 1995) and what Giddens (1991) has called the ‘reskilling’ of lay people in their engagement with, definition and management of health

and illness (Hardey, 1999). The third change refers to the ways in which lay people are required, but also perhaps actively embrace a turn towards taking greater responsibility for making new health technologies ‘work’: IVF is a case in point. As Roberts and Franklin (2004) show in their study of IVF clinics and the use of pre-implantation genetic diagnosis (PGD) to select embryos that are not carrying genetic mutations, PGD only ‘works’ where the prospective parents are active participants in managing and accepting the chronic uncertainties that still prevail with this treatment.

These three processes have then redefined the spatial, experiential and epistemic boundaries of conventional medicine and the clinic. I will be returning to each of these later in the book as we explore the implications of ‘technomedicine’, framed by the broader sociological issues noted above. The critique must be the attentive context of use of technologies to reflect any notion of technological determinism across different contexts (be these clinics or countries). It must explore the ways in which users (patients, carers, clinicians etc.) make sense of technologies and how re-order the meaning of health. It must examine the expectations and hopes that surround them, and the subtle and not so subtle forms of inequity and insecurity they create.

There is one area that will figure in only a minor way in this book and this relates to the ethical aspects of the new technologies. This is clearly a crucial issue and one that has led to a massive growth in literature that asks what are the effects of these systems on the rights of the individual and on the obligations of the state. Much of this growth has been in the field of bioethics particularly the so-called ELSA (ethical, legal and social aspects) of contemporary genetics. This text is a sociological and not ethical critique: where I do discuss ethics it will be to note the ways in which ethical and scientific discourses *co-evolve* as quandaries are resolved, boundaries redrawn, regulatory goalposts moved. Regulatory agencies change as they redefine what is possible and permissible, what is proscribed and what off-limits.

Structure of the book

The book is made up of seven chapters. The material for these chapters is informed by UK research that I was privileged to help steer as Director of the Innovative Health Technologies Programme supported by the ESRC, but also by a much wider body of literature. After this introductory chapter, the next two (linked) chapters explore some of the main institutional and organisational drivers that lie behind the

emergence of new health technologies. Chapter 2 examines the role played by two actors – the clinical professions and the state – that have historically been and are today central to the process through which new health technologies are crafted, developed, deployed and evaluated. The state/profession relationship was tied to a range of factors associated with the regulation of medicine, the emergence of the welfare state, the standardisation and delivery of care at primary (general practitioner) and secondary (hospital) levels, and broader public health programmes that were tied to preventative medicine (such as vaccination). Both national and international government agencies (e.g. the World Health Organisation, the European Union) seek today to invest in technologies in such a way as to provide more effective as well as more efficient systems of health care. The mantra of the day is ‘evidence-based medicine’, that is health care that can be shown to be based on robust and reliable information and research. This is then supposed to guide clinical practice on the ground. For their part, clinicians either individually through their own research or collectively through their professional bodies, develop and oversee the use of novel techniques in the clinic.

Paralleling state and professional groups in the production of new health technologies is the wider corporate innovation system that plays a key role in producing them, the private sector of pharmaceutical and ICT firms and those operating in the made up especially of medical devices markets. Chapter 3 summarises the main changes in the role of corporate innovation in shaping the meaning of disease and health disorders and their treatment. The largest firms are of course global actors and will try to ensure that their products sell equally well wherever possible. At the same time, these firms are well aware that their markets can vary considerably. This may result from different procurement regimes (from fee-based, market systems through to fully socialised (national) health systems), different ethical regimes and differential abilities to pay (for drugs etc.). The globalisation of health technologies does not, therefore, necessarily mean among less prosperous countries the globalisation of a standard price that health procurers or individuals must pay for a specific product or technique. This is especially true in the area of pharmaceutical drugs where government health authorities in a number of high-income countries determine a reimbursement level which drugs suppliers complain is much too low. This complaint has often been made, for example, by US drugs companies against a number of richer European states. The chapter will explore the role of private sector innovation in the key areas sketched out earlier: genetics, informatics

and tissue engineering. In turn it asks about the role of the state and regulatory regimes (national and global) that are charged with the task of managing risk and fostering innovation.

Chapter 4 discusses current social science literature on the body and our engagement with and management of illness, disease and treatment in light of the changes described in the preceding chapters. Most importantly, this leads to a revisiting of the long-established literature on ‘the sick role’ and ‘illness behaviour’. This work has been central to much of medical sociology but has tended to neglect the role of technologies (other than in the specific field of reproductive medicine) and has, understandably, been confined to conventional doctor–patient relations and narratives found therein. New technologies reshape the relations/their narratives and thereby render new possibilities regarding the sick role itself.

This leads us, in Chapter 5, to consider what might new technologies mean for the delivery and management of health care? The Chapter is especially interested in issues surrounding primary and secondary care, and is so on a comparative (international) basis. Computer aided support systems (increasingly commonplace in health delivery – such as the United Kingdom’s NHDirect, or the internationally common CASS tools used in patient care planning and so on) disturb boundaries between professional and patient, redefine the professionals expertise, and create both tensions between as well as empower those involved. In technology-rich environments such as these, nurses’ interaction with decision support leads to some unanticipated outcomes. I go on to ask what sort of discourses of governance have been created to oversee and regulate a more heterogeneous and risk-laden health care system.

The penultimate chapter will explore what I call the ‘new sick role’, wherein patient and activist groups mobilise this role in different ways to both secure or repel medicalisation. I also examine what happens when the role is denied to those who seek it and how new technologies can create competing definitions of what a condition might mean for different patients.

The final chapter will summarise the broad themes of the book and return to wider debates within social science theory about the ‘technologisation’ of health culture and the loss of traditional trust within expertise. It argues that innovations today have disturbed the body, medicine, health/illness experience relationships and suggests that health, like many other arenas of social life, is as Bauman has argued, increasingly and chronically disembedded from conventional

community, professional and institutional relationships. Despite such shifts, I return to the question of ‘novelty’ and show in the chapter how we need to assess both the discontinuities and continuities in health technologies and their deployment, and that both aspects characterise the ways in which patients and practitioners experience innovative health technologies.

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