

# The British Journal of General Practice

## viewpoint

### Patenting genes: a dangerous EU directive

Advances in genetics have the potential to provide better health for all. The WHO estimates that mortality, disability and reproductive fitness can be ameliorated in just under one-third of single gene disorders. About 50% of congenital abnormalities, 10% of inherited diseases, and 2% of chromosomal disorders can be treated or corrected.<sup>1</sup> Prevention or cure of common cancers is among the prime objectives of gene technology. Obstacles to research collaboration and free exchange of knowledge in this field are therefore to be deplored.

An EU directive<sup>2</sup> is to be implemented by 30 July 2000. One of its main purposes is to harmonise European patent laws with those of the US and Japan. Article 5 reads:

1. *The human body, at the various stages of its formation and development, and the simple discovery of one of its elements, including the sequence or partial sequence of a gene, cannot constitute patentable inventions.*
2. *An element isolated from the human body or otherwise produced by means of technical processes, including the sequence or partial sequence of a gene, may constitute a patentable invention, even if the structure of that element is identical to that of a natural element.*
3. *The industrial application of a sequence or partial sequence of a gene must be disclosed in the patent application.*

The key conflict is between the first and second paragraphs. The latter effectively creates a loophole whereby, if any technical process (such as a diagnostic test) can be based upon a specific discovered gene sequence, then not only can the process be patented but so can the gene itself, effectively conferring upon the patent-holder ownership and control of all subsequent developments that may stem from knowledge of its sequence.

Within the medical profession there is fundamental opposition to the patenting of basic scientific knowledge, such as human gene sequences, because of the consequences for the future development and application of that knowledge. Traditionally, much medical research has been conducted through collaboration and the sharing of information. It is vital that this should not be compromised by commercial interests.

One American laboratory<sup>3</sup> has obtained patents for two breast cancer genes and claims exclusive rights to commercialise laboratory testing services, diagnostic kits and therapeutic products dependent upon these DNA sequences. Institutions must, in future, send their samples to this company for testing.

If knowledge is patentable in this way then the patent-holder may gain a monopoly position for development and the costs of health care. They may even decide to block both clinical services and the development of new treatments. The monopoly would extend even to applications of the gene sequence totally unforeseen by the patent holder. If, for example, the RET gene had been patented for papillary thyroid cancer then the owner would have the patent on multiple endocrine neoplasia type 2 and Hirschsprung's disease.<sup>4</sup>

We maintain that human genes should not be considered the property of any one scientist or institution. The knowledge of our common heritage should be open to all researchers/scientists and clinicians for the benefit of mankind. A clear distinction can and must be drawn between technical processes/inventions that exploit gene sequences and the sequences themselves. Then it should not be beyond the wit of legislators to find acceptable ways to protect the legitimate commercial interests of high tech companies.

Terje Vigen, Neva Haites, John Burn, Pål Møller, Michael Steel

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## The Back Pages...

'... a difficult tension exists between a consumer's demand for informed participation, and a patient's need to feel supported in illness ... yet shielded from the anxiety of ambiguity'

Glyn Elwyn  
*Explaining Risks to Patients*  
page 342

'... livers follow a cannibal logic ...'

The Liver and the French  
*Crise de Foie*  
Iain Bamforth  
page 344

'I'm a columnist: I prickle; therefore I am'

Neville Goodman  
page 351

## contents/Gene Fest

- 358 **news**  
Cross-cultural medicine, and PCG boardgames plus **singh** slipping up
- 340 **theories of change 4**  
*Change and organizations*  
*Culture and context*  
Greenhalgh
- 342 **postcards 4**  
*Explaining Risk to Patients*  
Elwyn
- 344 **essay**  
*Crise de Foie*  
Iain Bamforth
- 346 **digest**  
Kay enraptured by competent genetics, Reilly communing with patients, Barbour on trickier specimens, Minns on *American Beauty*, Singh on *Magnolia*
- 348 **reflection**  
A grateful McCormick, and Philipps in Love
- 350 **matters arising,**  
plus Blisters
- 351 **diary**  
plus a cynical **goodman**  
plus poetry by **bolton**
- 352 **our contributors**  
plus **charlton** in bed  
with philosophers

### Management of foot care in diabetes

The College has produced a new guidelines leaflet for the prevention and management of foot problems in Type 2 diabetes. It has been developed in association with The British Diabetic Association, The Royal College of Physicians, The Royal College of Nursing, and a range of other professional organisations.

The guidelines have been produced following a review of all current international evidence, with Professor Allen Hutchinson FRCGP heading the team. The guidelines make recommendations on case management for people with Type 2 diabetes and are set out with sections on various stages of foot problems. Each section gives a synopsis of the current evidence and provides recommendations and management for each stage of the foot problem.

The leaflet is available on request from the RCGP at Princes Gate.

## Cross-cultural Primary Care Course

Primary health care increasingly takes place among a diverse and heterogeneous patient population, with a wide range of belief systems and health practices. In the community, patients now come from a variety of social, cultural, religious, ethnic, regional, and educational backgrounds, as well as different lifestyles and choice of self-treatment. In many cases this has led to problems in communication between patients and health professionals, as well as inequalities in health care.

### Aims of the course

To equip those working in primary health care with the skills necessary to understand the health beliefs and practices of different patients and communities and how these may differ from their own

To help increase communication between providers and clients in primary health care

To provide the opportunity for developing a more reflective and self-aware primary care

To understand the roles of participants own culture, social class, gender, age, and education in communication problems in primary care.

To provide participants with an opportunity to understand their own experiences of cross-cultural issues in primary health care

To integrate this experience with the concepts and research evidence from medical anthropology and other social and behavioural sciences using a multi-disciplinary approach

To help design culturally appropriate intervention, health promotion strategies, and patient participation in primary care

### Course structure

Each session will consist of a lecture on the relevant topic, followed by a discussion of key texts. It will provide participants with the opportunity to integrate social science theories with their own clinical or administrative experience, and the problems that they have encountered in the delivery of primary health care.

Topics covered in the course include cross-cultural aspects of:

Patients explanatory models of illness  
Body image and interpretation of

symptoms

Family structure and family health  
Pregnancy, childbirth, fertility, and infertility

Death, dying, and bereavement

Alcohol, tobacco, and drug abuse

Use of non-medical health care

Cross-cultural psychiatry

Nutrition, malnutrition, and dietary taboos

Migration, refugees, stress, and disease

HIV/AIDS and other sexually transmitted diseases

### Other information

The course is open to all those working in primary health care settings, whether in the UK or abroad, including GPs, nurses, health visitors, counsellors, pharmacists, administrators, and health planners, as well as those working in community paediatrics, psychiatry, social services, and the voluntary sector.

The course will be taught by Dr Cecil Helman, senior lecturer in the The Department of Primary Care and Population Sciences, Royal Free and University College Medical School, and associate professor, Department of Human Sciences, Brunel University. Some sessions will be given by guest lecturers.

The course will take place in the Archway Campus of the Royal Free and University College Medical School, Holborn Union Building, Highgate Hill, London N19 5UA.

The first course will start in May 2000. It will consist of five full-day sessions, from 10.00am to 4.00pm, on consecutive Tuesdays. For dates of subsequent courses, please contact the Course Office.

The cost of the course is £600 per participant. Partial bursaries may be available. For details, please contact the Course Office.

### Postgraduate Education Allowance

A certificate of attendance will be given to all participants. PGEA approval has been applied for.

### Further information

Ms Andy Kyriacou, Department of Primary Care and Population Sciences, Royal Free and University College Medical School 2nd Floor, Holborn Union Building, Highgate Hill, London N19 3UA.

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## GOV!

### The PCG clinical governance board game

The PCG Resource Unit is a small unit, working in the Public Health Resource Unit in Oxford. It is funded by a grant from South East Region R&D. The unit has been looking at a number of aspects of PCG development, in particular the support of clinical governance in primary care. More information about their work can be found on their web site at [www.phru.org/pcgru](http://www.phru.org/pcgru). As a spin-off from their recent work they have developed Gov! .

Designed as an educational tool, Gov is proving to be an extremely popular and successful way of developing multi-professional understanding of the issues of clinical governance in primary care. It has been used at a series of primary care workshops to promote an understanding of clinical governance. The evaluation by participants has been very positive ...

*“very thought provoking”  
“good fun but with a serious message”  
“needs to be sent to all PCGs and Health Authorities”*

Anyone with a need to understand clinical governance issues better will want to play this game, e.g. members of PCG Boards and practice teams, GP registrars, and organisations working with primary care.

*Object of the game:* Players work in teams to construct outline solutions to hypothetical problems or strategic issues.

Each game pack includes two laminated A3 size boards with two full sets of cards, dice, and counters, full instructions, and crib sheets for game facilitators.

The game could be readily adapted to other settings or to cover issues particular to one profession (e.g. dentists). Gov! is recommended for all PCGs, Health Authorities, Local Authorities and Community Trusts. South East Region NHS Executive generously funded every PCG and Health Authority in the Region to be sent a copy. However, if you are not in this region you can obtain a copy of Gov! , by contacting Toby Holman on 01865 226987 or at: [toby.holman@phru.anglo.nhs.uk](mailto:toby.holman@phru.anglo.nhs.uk). A charge of £25, to cover costs, will be made.

## surinder singh

### A man with a painful limp

I remember him well, limping in several times last year having fallen awkwardly at work and I thought I had done the right thing. I had known the man a 31-year-old patient for over five years; his English was not perfect but more than adequate for ordinary daily conversations and consultations.

The first time I saw him with his painful limp I made sure he was well; he could move his joints and I advised that he should use some painkillers since I thought the work-related fall had resulted in a pulled muscle .

I mentally noted his ethnic group and suggested that he had baseline blood tests nothing fancy just a full-blood count and ESR and basic electrolytes. I think I even asked what he thought it was and yes, he agreed, it was a pulled muscle . The one difficult and distracting sign was his limp as he pointed out to me many times an old ankle injury on the same side from his days in a country south of the Equator. Not easily forgotten, but this was the first sign that all was not well; almost a type of Murphy's law in waiting: If it can go wrong, it will.

Well, I saw him again and yes, the ESR was raised (to 61), so I did what all good academic physicians advise: reassess, repeat, and review. Two weeks later I saw him again; the ESR had fallen to 31 but he said that things were the same . He then told me he had private cover through work and I took full advantage of this; he was seen the following day by an eminent local consultant.

I needn't have worried the orthopaedic surgeon agreed with everything I had suggested and fairly swiftly discharged him from the clinic. And anyway, the patient appeared better he was not back to his best, but then how could he with a seemingly chronic limp?

You can imagine my surprise when, two months after last seeing him, my partner, who has a well-known, instinctive nose for those types of rare and glorious diagnoses, saw him with a hard, tender lump mid-way down his left thigh. The rest, as they say, is history. TB osteomyelitis.

What are the lessons here? I am unsure except it seems banal to talk about high index of suspicion, and equally banal to acknowledge that TB is very common in the non-indigenous population. I thought I had done enough to consider and attempt diagnoses after all, why else would I bother to repeat blood tests, order X-rays (yes, these were all normal), and arrange follow-up. The concept that patients in general practice are seen early in their disease is worth noting, so arrange follow-up where necessary is a vital lesson for would-be GPs.

Perhaps, despite a patient's wellness, we are supposed to continue to search out disease where there is no illness or signs of sickness (what would anthropologists think of this approach?). Who knows? Or perhaps it is simply that no matter how competent, professional, or on guard we are, medicine is at times genuinely difficult and occasions like this are designed to deter a natural, time-dependent complacency.

Interestingly, I have only seen him once since the diagnosis but he appeared to harbour no ill-feeling towards me more a wariness of tests in general and hospitals. His wife sees me fairly regularly and hardly ever mentions the episode.

I won't forget the family in a very long time.

*(Patient consent received.)*



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## The 'anthropology' of organisations

Anthropology defined by the Oxford English Dictionary as the study of mankind, especially of its societies and customs has come a long way since the colonialist days when researchers in pith helmets sat among the natives and made notes on their strange behaviour. The modern approach to anthropology has three important features. First, anthropology need not (and should not) be applied only to the study of other people(s). Rather, it is an important tool for revealing the basic assumptions and unwritten rules of the groups, organisations, and societies in which we ourselves operate. The study of one's own cultural norms and expectations requires a dispassionate, distancing approach, which has been described as making the familiar strange.

Second, the customs and ideologies that make up a particular culture are not static. All societies, and all organisations, are constantly evolving and changing. A custom, ideology, or belief that is readily demonstrated in 2000 may be less evident in 2005 and hardly detectable in 2010 though the time course of major cultural change is generally measured in decades or centuries. Third, while culture is an important influence on the beliefs and behaviour of individuals, it should not be thought of as determining those beliefs or behaviour. To a greater or lesser extent, the individuals within a society, organisation or group choose to conform to, or resist, its agreed frame of reference and unwritten rules of behaviour.

## Organisational culture

Anthropological analysis accepts that there are three levels of cultural behaviour: what people say they do (for example, during an interview), what they are actually observed to do, and the underlying belief system which drives that behaviour (Hall's primary level culture).<sup>1</sup> Furthermore, the behaviour of any individual is crucially influenced by the wider context in which the behaviour takes place. Edgar Schein, Professor of Management at the Massachusetts Institute of Technology, applied Hall's framework to the culture of organisations, as shown in Figure 1.<sup>2</sup> Hunt has argued that an organisation's culture is essentially determined by four variables: people (who works there), strategy (the organisation's broad goals and how it plans to achieve them), structure (how the organisation is made up and what technical facilities are available), and external pressures (Box 1).<sup>3</sup>

## Handy's taxonomy of organisations

Charles Handy, drawing on the work of Roger Harrison, suggested that all organisations can be broadly divided into four cultural types:<sup>4</sup>

1. *Power culture*, in which the organisation holds entrepreneurial values and is built around a charismatic leader (e.g. Microsoft, Virgin). Control is exercised mainly by the selection and deployment of key individuals; and influence is achieved mainly through person power.

2. *Role culture*, which most of us would call bureaucracy and identify with large health care organisations (e.g. traditional NHS hospitals), is characterised by a logical and visible structure. Roles, and lines of accountability, are tightly defined by written job descriptions. The role culture is essentially designed for programmed work and operates well in stable, predictable and controllable environment.<sup>4</sup>

3. *Task culture*, in which the organisation, and the individuals and groups within it, are oriented towards doing a job or completing a project. This organisation tends to be extremely flexible, group-oriented, and highly responsive to change. However, it runs into problems when money and people have to be rationed, whereupon individuals become demoralised, teams within the organisation are forced to compete for resources, and top managers find themselves imposing control through old-fashioned means. In short, and of crucial importance in today's NHS, the task culture is inherently unstable and tends to change to a role or power culture where resources are limited.<sup>5</sup>

4. *Person culture*, in which the organisation itself is barely visible and exists only to serve the individuals within it — classically illustrated by the hippy commune in which the organisation is no more than a place for the individual to do their own thing. The idiosyncratic senior partner who refuses to adapt to new rules typifies the person-oriented individual operating within a role culture and, Handy warns, such people can be extremely difficult to manage.

In general, an increase in size pushes an organisation towards a role culture, as many of us have found when a singlehanded or two-partner practice expands to three or more. Rapidly changing technologies require a task or power culture, but routine and programmable tasks (such as many aspects of monitoring, audit and quality control) may be better suited to a role culture.

## Culture clashes within and between organisations

Starting a new job, coping with a change of management, or attempting to work across an interprofessional or inter-organisational interface, can often be unsettling and frustrating.<sup>6,7</sup> Discordance in aspects of organisational culture listed in Box 1, perhaps particularly the unspoken values, assumptions, and systems of meaning that

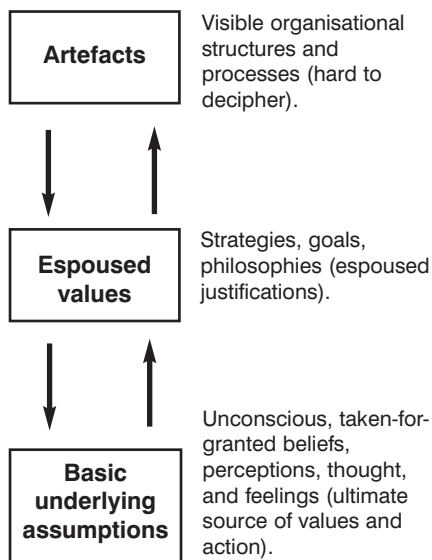


Figure 1: Schein's three levels of organisational culture



underpin behaviour and decision-making, leads to a feeling that they are irreconcilably different from us and that progress cannot be made (at least, not until they come to their senses or are coerced into acquiescence).

Perhaps the most frequently encountered clash in today's NHS is that between professional and management cultures (Boxes 2 and 3). Another, frequently played out in the arena of evidence-based practice (see case study), is between academic culture (with its emphasis on controlled and measured interventions, rigour, precision, and reproducibility) and service culture (with its emphasis on making the best of the materials and information available, maintaining harmony and job fulfilment among staff, responding flexibly to individual needs, and keeping the customer satisfied). Finally, there is the clash between the care culture of traditional nursing (which values support, empathy, effective communication, and time) and the cure culture of acute medicine (which values accurate diagnosis, active intervention, and rapid and measurable changes in the markers of disease).

### Conclusion

Both organisational and professional cultures are deep seated, pervasive, complex, and resistant to change. As Box 1 shows, one important feature of organisational culture is the collection of words, interpretations, stories, and myths with which we construct the social world in which we work.<sup>8</sup> The palpable sense of panic in many medical circles is partly owing to the prevailing discourse on clinical governance (quality, accountability, risk management, productivity), which reflects the language and value system of managers rather than health professionals. There is no quick fix to this cultural dissonance, but an important start must be to construct and disseminate a narrative that gives professional meaning to the changes required of us all a task that some writers have, thankfully, already begun.<sup>9,10</sup> The next article in this series considers additional strategies for change.

**Trish Greenhalgh**

### Acknowledgement

*I am grateful to Fraser MacFarlane and Alec Logan for helpful comments on earlier drafts of this paper.*

### Case study: Introducing evidence-based medicine in a traditional general practice

Dr Tessa Myers, 32, is a part-time lecturer in an academic department and a new partner in general practice. She is keen on evidence-based medicine and is already attempting to introduce major changes to her practice, including a computer upgrade, a link to the Internet, routine use of evidence-based guidelines, generic prescribing from a practice formulary, and a weekly clinical meeting in which the management of particular cases is reviewed against best research evidence obtained on-line from the MEDLINE or Cochrane database.

Tessa's three partners (aged 63, 55, and 39) cannot seem to take this activity seriously. Denis Higgs, the senior partner, has begun to make jokes about whether the coffee is evidence-based. He reminds Tessa that he gets specialist advice whenever he asks for it from the appropriate consultant, that no bureaucrat with an MBA is going to tell him what to prescribe for his patients, and that the practice as a whole "has a policy of binning guidelines". Clinical meetings already happen once a fortnight in partners' houses, and cases are discussed in congenial surroundings over a meal. Tessa has prepared a written case for the changes she proposes, including a detailed calculation of how many premature deaths might be prevented if their management of hypertension became evidence-based.<sup>12</sup> She is furious that her background paper has not even been considered by her partners.

This case scenario demonstrates the very common clash in values and perspective between traditional clinical practice and the 'evidence-based' approach. In proposing what she sees as simple changes to 'the way things are done around here', Tessa is in reality mounting a fundamental challenge to the other partners' basic assumptions and values. For example, her 'solution' devalues the experience and expertise of senior colleagues, removes 'clinical freedom' (the GP's right to prescribe what he or she feels is the best medication for the patient), introduces an entirely new framework for decision-making, requires adjustment to new technologies, and undermines long-standing internal and external hierarchies and networks.<sup>13</sup>

If she is to succeed in her quest to make the practice more evidence-based, Tessa must adopt a realistic strategy and time frame for addressing cultural change.<sup>8</sup> She should begin with an achievable and non-threatening change that is more in step with the existing practice culture — such as offering summaries of relevant research reviews as part of clinical case discussions in existing partners' meetings. She might also ask her consultant colleagues to explain that the advice they offer is from the same evidence-based sources that she wishes to install in the surgery. Finally, she might challenge her partners' protectionist attitude to clinical freedom obliquely rather than head-on — for example, by offering to help them all 'get on top of' the forthcoming revalidation agenda.<sup>9</sup> In this way, a proactive approach to evidence-based practice might be seen as a potential tool for protecting the GPs' clinical autonomy rather than as a threat to their core values.

### Box 1: Components of organisational culture (adapted from Hunt<sup>3</sup> and Bate<sup>6</sup>)

- The 'atmosphere' of the organisation;
- a system of meanings and interpretations;
- The code for 'how things are done around here';
- Unspoken values and assumptions that underlie how things are done (see Figure 1);
- Standards used to define good or bad performance;
- Ways in which individuals are recruited, trained, promoted, controlled and rewarded;
- Stories and myths about what happened to particular individuals or teams that behaved in a certain way;
- Organisational rituals such as journal clubs, ceremonies, social events, and so on;
- Subcultures and countercultures that exist in parallel with the 'official' version of the above.

### Box 2: Features of professionals (adapted from Simon<sup>11</sup>)

*Professions possess a body of knowledge and skills based on long periods of training and demanded by society. They share a code of ethics that indicates how patients or clients should be served and the social attitudes that should be accepted. A profession is defined in terms of six key features:*

1. A body of knowledge or skill held as a common possession and united by extended effort.
2. An educational process based on this body of knowledge for which the professional group as a whole has a recognised responsibility.
3. A standard of qualification for admission to the professional group based on character, training and proved competence.
4. A standard of conduct on courtesy, honour and ethics, which guides the practitioner in his or her relationships with clients, colleagues and the public.
5. A more or less formal recognition of status by colleagues and by the state as a basis of good standing.
6. A professional organisation or group devoted to its common advancement and its social duty rather than the maintenance of an economic policy.

### Box 3: Features of managers (adapted from Simon<sup>11</sup>)

*Managers' first allegiance is to their organisation. The knowledge they possess is derived from on-the-job training and experience within the organisation. Management is characterised by:*

1. A broad body of expertise that is specific to a particular organisation and transferable within that organisation.
2. A training process based on organisation-specific knowledge for which the organisation generally takes responsibility.
3. A programme of career advancement focused on the internal labour market (i.e. within the organisation).
4. An internal system of discipline implemented via line managers.
5. A standard of conduct and code of ethics oriented to the advancement (usually economic) of the organisation.

# Postcards from a New Century

## Explaining Risks to Patients

This article is the fourth in a series of 12 commissioned and edited by Paul Hodgkin, co-director, Centre for Innovation in Primary Care, Sheffield, and Alec Logan, Deputy Editor, British Journal of General Practice, London.

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Only one thing is certain, my biology teacher used to say: that nothing is certain. Having worked for over a decade in clinical practice, the implication of this view is coming home to roost as patients have more to say about the decisions that affect their health care. But a difficult tension exists between a consumer's demand for informed participation and a patient's need to feel supported in illness, directed towards best solutions and shielded from the anxiety of ambiguity. This gives uncertainty a central position in many consultations and can create difficulties when practitioners try to share data (if available) about an intervention's harms and benefits. This uncomfortable face of professional honesty is part of a larger pattern of course, a shift towards more equal partnerships within clinical exchanges.

It is within this general trend that we can also observe professions being gradually demystified. In 1972, Johnson published a short monograph which ascribed three broad phases occurring within professional organisations, namely, patronage, collegiate, and mediated.<sup>1</sup> These three phases can be easily seen within medicine. It was patronage that largely supported physicians in the seventeenth century, when the wealthy sought their advice. By the eighteenth century, physicians had engineered a collegiate profession. This trend was accompanied, indeed fuelled, by the rise of hospitals, colleges and medical schools - a process that had been spectacularly successful at generating a club attitude to the way medicine is practised and governed. The third phase is only just becoming visible and involves a third-party mediation of the processes involved. Some see this phase as one of de-professionalisation. Doctors are increasingly managed, appraised, directed by guidelines, and the basis of their expertise access to a unique bank of knowledge is being rapidly undermined as the Internet

turns the tables on the difficulty of obtaining specialist information. Add to these accelerating trends the move to investigate professional activities (as in Bristol for example) and it becomes obvious that clinicians face a situation where the profession of medicine (like others) is being re-defined into an accountable discipline that contains tightly monitored and regulated processes. Acting as additional fuel, it is widely recognised that the influence of information networks, now accelerating as wireless access increases, will accelerate the shift of power within clinical consultations.<sup>2</sup>

A third trend that requires clinicians to grasp the nettle of risk communication is the increased availability of technologies that predict and prevent.<sup>3</sup> The last few decades have been notable for their emphasis on anticipatory activities such as cervical screening, estimating cholesterol levels, providing breast mammography, undertaking blood pressure monitoring and so on. The new genetics heralds another wave of potential predictive interventions, and although the ethical and practical implications are not yet fully realised in many of these areas, consumers naturally hope for reassurance by pursuing negative tests. This trend inevitably drives both the development of investigations, such as the BRCA1 gene identification kits, and the consequent demand for them, despite their shortcomings, to the point that many such genetic tests are now commercially available online.

There are signs, however, that the looming issue of informed consent may yet raise the importance of explaining risks into another dimension. A patient in the United States has successfully prosecuted a case claiming that she was not fully informed about the chances of a false-negative result. It is already known that patients are becoming more aware of the

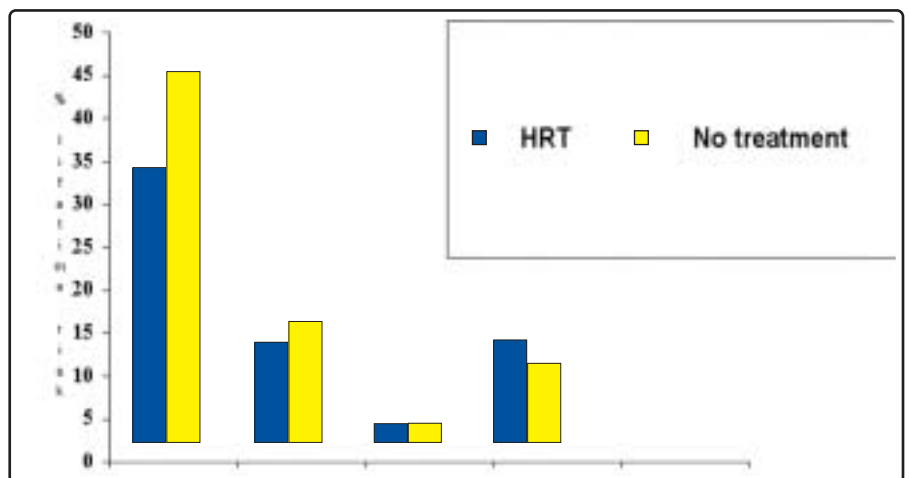



Figure 1: Risks and benefits of hormone replacement therapy taken for five years.

fact that tests such as the prostate specific antigen are not grounds for blithe reassurance when results are within normal reference ranges. The spectre of medico-legal surveillance for false-negative or false-positive outcomes may well be the signal that pushes clinicians to take more time to ensure that patients become fully informed about the lack of precision of both investigations, and the possible harms that attend most medical interventions.

The case for needing to explain risks and arrive at shared decisions becomes more imperative when such issues are raised, even if this is contrary to the level of support, guidance, and transfer or responsibility for decision-making that patients often prefer, especially when ill or anxious.<sup>4</sup> How then should practitioners go about it? There are three essential components. Time, communication skills,<sup>5</sup> and accurate data clearly presented so that both clinicians and patients alike feel that they understand both the relative and absolute risks of the possible outcomes, and have taken into account the biases that the framing of information can introduce (i.e. the difference between telling someone that they have a one-in-ten chance of dying as opposed to nine-in-ten chance of living).<sup>6</sup> Clinicians will need to engage with patients to carefully distinguish between two fundamental concepts, which Adams has referred to as objective risk — the risks that experts talk about, and perceived risk — the lay person's often very different anticipation of future outcomes.<sup>7</sup> Within this context, there is also a need for both government and consumer groups to be realistic about risk levels. The extremely low risk of contracting new variant CJD by eating beef has completely obscured debate about other more common and dangerous exposures (*E coli* transmission by food handlers or routine antibiotic dosing of livestock). The risks of medical interventions need to be considered within our broader societal context and compared with the range of risks we face on a daily basis.<sup>8</sup>

This process takes time. Decision-boards, interactive computer packages, and instructional videotapes have been used extensively as a means of enhancing (and often substituting) the normal face-to-face exchanges.<sup>9</sup> They will become even more commonplace as technological access points to the Internet become as commonplace as telephones are today. The challenge for clinicians will be to adapt and use these technologies and be prepared to undertake searches for and appraise primary sources of evidence when no readily available digested packages of data exist.<sup>10</sup> In short, to adopt an evidence-based patient choice approach to clinical practice.<sup>11</sup> The fact that the current health service finds it impossible to match the

## Getting personal



The Internet may have shrunk the world but communication with inanimate objects in the here and now remains frustratingly obdurate. Embedded chips in everything from the door to the microwave may be part of the answer but what about all the increasing equipment that we choose to carry — laptops, mobiles, beepers, electronic diaries? Bodies conduct electricity — so why not do away with wires and get the body to carry the signals? 'Personal area networks' based on this idea aim to link all the gizmos you can carry into a single seamless network knitted together by your own body. You become the circuit that connects your central processor to your diary, your discrete phone headset to the digital display on your wrist. Chic, but perhaps a little self-indulgent? Not so — meet someone else wearing a personal network and a handshake may enable you to exchange data. Put your hand on a door sensor and it will recognise your network-generated signature. So is this going to lead to a heavy belt full of fashion-conscious electronic accessories? Probably not. It turns out, for example, that the best place to put one of these truly personal computers is in the heel of your shoe. Shoes are one of the few pieces of clothing we almost always wear, and the flexing of the sole provides an ideal source of energy — no more clunky batteries. Such deeply personalised connectivity is going to profoundly alter how we interact with other smart artefacts in the environment. Since such networks could also monitor a range of biological parameters, a handshake at the start of a consultation might inform you of a patient's blood pressure. Or mutual anxiety levels — no more disguising your heartsink reactions. Such monitoring might raise health surveillance to new and possibly uncomfortable levels. Or make biofeedback control of some symptoms an everyday therapeutic option. It might even help us communicate better about risk as individualised data and graphics become ever easier to personalise and deliver to patients.

Paul Hodgkin

speed of advances in information technology will need to be tackled by policy makers. Clinicians faced with knowledgeable patients and increasingly aware of their medico-legal responsibilities will yearn for much more than simplistic guidelines. They will need to be able to have immaculate data retrieval systems so that information about the harms and benefits of hormone replacement treatment are at their fingertips. The relative risk of developing breast cancer may increase by 30% or so after taking HRT but the absolute risk levels are low, and consist of the difference between 10% and 13%. Is this level of risk acceptable to achieve the cardiovascular and bone preservation benefits portrayed in Figure 1, bearing in mind that at least five years of therapy would be required?

A simple histogram may be relevant to a clinician who is conversant with visual displays of numerical information but many patients will find the concepts difficult to comprehend. Tailoring these broad population risks into more personal risk assessments (using family history and, in this scenario, even genetic screening tests) will require some decisions to be structured into a series of consultations, broadly based on the skills and stages of shared decision-making.<sup>12</sup> Achieving informed decision-making (robust enough to withstand legal scrutiny) will change the way clinicians handle complex consultations. Clinicians will probably need

to be conversant with a range of decision-aids so that they can either use them at the desktop or ask the patient to spend time in the practice information room. This room is equipped with interactive screens where validated decision pathways can be explored. These multimedia simulations of potential futures will intersect clinical interactions and patients will co-produce their management plans, in much the same way that consumers now collaborate in the design of a computer ordered within an interactive web-site.<sup>13</sup>

For most practitioners, even those who have developed a patient-centred consulting style, this elaboration of decision-making will be challenging. For many practitioners it will mean abandoning their assumptions about professional status and behaviour. The greatest dilemma will be to remain flexible as patients develop these skills of assessing risks and benefits. There is no doubt that many people are ambivalent, even resistant to the difficult tasks of becoming involved in decisions. But the ethical climate is changing and clinicians should learn to be alert and flexible to the preferred role of individual patients in their health care management. What is difficult to comprehend, however, is how this new information age fits into a publicly-funded health service that is audibly creaking under the weight of the demands placed upon it.

Glyn Elwyn



## Crise de Foie

**Mythic medicine:**

Iain Bamforth looks back on three years of practice in France, and the weight of the liver in French culture. Amateur etymologists (and those who can still remember school French) may be interested to know that the French word for the liver (le foie), which is allegedly derived from the Greek term *sykoton* meaning stuffed with figs, is homophonic with something in short supply these days: faith (la foi).

Until the twentieth century the history of making a living out of other people's bad days wasn't an especially edifying one. Now that medicine seems to be limited only by its means, perhaps it's the vestigial memory of quackery, barber-shops, and that odd business with leeches which makes the profession unwilling to admit there are things about the body that leave its observer, if not its tenant, nonplussed. Doctors, who, with the blessing of society at large, now instinctively think of themselves as progressive people at the cutting edge of the possible, get embarrassed and hot under the collar about such nonplussing, particularly when it comes from the patient who may happen to be speaking a foreign language.

When I started up my own practice in Strasbourg, where many of my patients do indeed speak in strange tongues, I suffered such a double embarrassment; not merely one over commonplace terms, but about the kind of bodily reality those terms expressed.

The embarrassment was due to the fact that I didn't know what a *crise de foie* was or how to deal with it. In all my experience in medicine, from the mother-country to several of its English-speaking daughters, I'd never come across an hepatic storm, an acute liver, bile acid build-up or anything else resembling this liverish state of being. Even my own sister, who wrote her PhD thesis on one of the major detoxification

pathways in the liver, the cytochrome P<sub>450</sub> system, had never heard of it. Something rare, such as acute intermittent porphyria, about which there's a film (*The Madness of King George*), but a *crise de foie*? It was all the odder that such an alarmist dare I say Pascalian label be given to a condition that clearly wasn't in the least life-threatening or physically incapacitating: hadn't the patient just walked through the door unaided?

So I did some reading. It's what Cecil Helman, in his book *Culture, Health and Illness*, calls a folk illness, a configuration of symptoms with no expression in biomedicine, and for which a culture provides both an explanation and a method of healing. There are other similarly tenacious folk illnesses across the world: *amok* in Malaysia, *windigo* in north-eastern America, *dil ghirda hai* (sinking heart) in the Punjab, brain fog in parts of Africa, *nervios* in Latin America, and even colds and chills in the English-speaking world. By definition, each is embedded in its own uniqueness; and I was still no closer to understanding what a *crise de foie* might be. It certainly had its polypharmacy, like every other medical complaint in France: strange elixirs containing oligoelements in snap-open glass capsules and eupeptic granulates to be taken *ante cibum* that were unknown to chemists in neighbouring countries. That a symptom might be trivial

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is a value judgement not permitted to a nation of amateur body theorists. But what symbolic weight did the liver have for the French? Why was being liverish the *mal national*? Come to think of it, being liverish sounded too literary, too poetic, to be much of a symptom; in fact, it suggested port and portly gentlemen in one of Cruickshanks or Rowlandson's merciless copperplate etchings of quacks and society characters in the eighteenth century, when the cure was almost always worse than the disease.

One thing about reading, it takes you places where people don't even speak French.

A patient with a *crise de foie* always seems to have the following symptoms: he feels bloated, has a thick head (but not necessarily headache), waterbrash (a bad taste in the mouth), lassitude, and a general feeling of what Kafka once told his diary was seasickness on dry land. It seems to resemble what most stolid folk would call a hangover (*gueule de bois* in French) and doctor's dyspepsia, arriving like bad weather the morning after social occasions without necessarily having had anything to do with rapid induction of mixed-function oxidases. Hitherto, my examinations of such people have usually been as the phrase goes unrevealing. My response is usually to sound sympathetic and tell him (nearly always a him) to take a couple of paracetamol and change his diet. *Primum non nocere*. Some doctors even stick more out of curiosity than conviction, presumably an acupuncture needle into the dorsal side of the foot between the first two toes. The once famous moral tract *Traité de Médecine Générale* (still in print) recommends water only for 24 hours, vegetable broths, herbal teas, light meals, no alcohol and sleep, a regimen not likely to offend anybody's common sense. But I often have the impression that such a pragmatic response falls short of expectations, especially when the liver can excite such purple passages as this: Her Shen was low. This could be seen in the bronze colour of her face, the slightly rolled-back position of her eyeballs and her fatigued demeanour. Her pulse was wiry and rapid, indicating Uprising of Liver Fire syndrome (*Acupuncture in Medicine* 11.96).

True enough, Chinese meridians make a big deal out of the liver. But what turns this little outpouch of endoderm, tucked above the yolk sac stalk, into the seat of humanity? In physiological terms, the liver is the body's (extremely efficient) sewage-plant, protein producer, and sugar and fat regulator. It's also the biggest organ, and its right-regal size may well explain its preponderance in cultural affairs. A critical liver is a leftover from Galenic medicine and medieval theories of the spirits (in fact, Galen believed that the liver was the receptacle of the natural spirit, as opposed to the vital and mental spirits lurking in the heart and

brain respectively); but while a recent evening-long search through Rabelais provided me with lots of extravagant remedies and nostrums, and the splendid line for I love you with all my liver, nothing very clearly emerged which might explain the quintessential liver in all its majesty, nor all the sublime hot air it has given rise to in French medicine. I therefore concluded that, French or otherwise, the liver is a signal instance of how we all think magically about our bodies. Not that our bodies are magical, but nobody, not even the most brick-headed enzymologist, is likely to view his liver in terms which exclude its miraculous ability to exempt him from toxic lapses. My own explanation therefore errs towards the Promethean.

Everyone remembers one thing about Prometheus (forethinker): he had such a rush of feeling for early man (in mythology man always starts out as just man) that he gave him a spark of fire he'd stolen from Zeus as it slowly smouldered in a tube of fennel (a penis substitute according to Freud, though such a conflation would seem to overlook the dampening effect of the penis's other emanation). The myth is more intricate. Prometheus had been one of the assistants at the headbirth of Athene; later she'd taught him all the applied arts including architecture, astronomy, and navigation. Decently enough he passed them on to his creatures. But a piece of expediency led to his eventual downfall: he showed *Homo sapiens* how to leave Zeus the bones and gristle when the sacrificed animals were apportioned. Asked to adjudicate in a dispute at Sicyon, in the north-eastern Peloponnese, Prometheus flayed an ox and made two bags of its skin; one containing all the prime cuts with the tripe on top (in the hierarchy of organs the stomach was always the least favoured part), the other the bones hidden under a layer of fat. What the easily duped Zeus chose became the divine portion. According to Hesiod, in what is the first historical account we have of the myth, Zeus, very touchy about his status as top god, and not appreciating Prometheus's dupery, then decided as a punishment that humans would have to eat their meat raw. It was Prometheus's next act stealing an ember from the sun-chariot and wrapping it in a fennel stalk so that dads could forever after preside at the ceremony of the barbeque which brought out Zeus's really inventive side, his vindictiveness: he made the beautiful but simpering Pandora (all-gifts) a gift being, as the German language reminds us, nothing other than poison and sent her to Prometheus's brother, Epimetheus, who specialised in afterthoughts. Her receptacle, as we know to our cost, contained all the spites and evils, like Vice, Labour, Bipolar Disorders, and Geriatric Infirmary, that have subsequently plagued the world, and made lesser evils like doctors necessary in order to distract the spites from their original mission.

And once the spites had flown the jar and nearly caused Pandora and Afterthinker to die from anaphylactic shock, what was left? A booby-prize called Hope, which must have been heavier than air to get stuck inside; it was the only thing left which prevented their descendants, driven out of their minds by the spites, from doing away with themselves. Prometheus pyrphoros, the Fire-Carrier, ended up clamped to a rock in the Caucasus, his liver being pecked out daily by an eagle and then regenerating overnight. Which sounds like the modern biomedical concept of the liver. Only the rock, insisted Kafka in his minuscule fable about Prometheus, is the really inexplicable part of the legend.

So much for Prometheus and the longwindedness of evolution, since the descendants of the eagle stopped pecking his liver and started nesting in his rib-cage, and Pandora's gift, it became clear in time, was a black box to tell us what had happened to the heroic days when the gods mixed it with humankind.

But the myth made me think of the French again, confused as only a deeply conservative people can be by their self-appointed role, for the last few hundred years, as the fire-carriers of modernity. Progress is no less an exhausting idea than its opposite: to think our bodies a metaphor for the decrepitude of the world. A *crise de foie* must therefore be a kind of chronological vertigo—a morning's retributive visitation for sitting down the night before to sup nectar, in that sense of complete and utter well-being the French exude only at the dinner table, as if magically ushered back from the state ruled by Reason to those lands of gastronomic abandon Cockaigne and Schlaraffia where the day's only order is the tripartite call to table. Botanisising with their palates, as it were, in a world sealed against phasal eating stations, buns on the run, and the golden M sign. Yet cuisine and apocalypse come together rather neatly in French consumptive habits, as seen to good effect in Marco Ferreri's painful film *La Grande Bouffe* (1973), in which three men asphyxiate themselves to death on every gastroglobal delicacy money can buy. Diagnosis? Fast food, slow food: myths are stratagems which enclose their opposites. And livers follow a cannibal logic. We have to sleep on them and they have to process those terrifying opposites, faith and doubt, which they do without fuss until dawn comes out, not rosy-fingered as Homer has it, but with a grey hair or two.

Now you know the answer to the biliously rhetorical question once posed as a title by the sociologist of man at the end of his tether, Jean Baudrillard. What are you doing after the orgy? Going to see the doctor, of course.

Iain Bamforth

## in brief

### *American Beauty*

**Sam Mendes, Cert R**

It is almost impossible that you will not have heard of this film yet, which has arrived from the US with more plaudits and awards than any for a long time. It is to the credit of Hollywood that it has made so remarkable a film, one that paints so grim a picture of the hidden horrors of the suburban dream.

As fast as the film debunks the traditional bourgeois life, it applauds alternatives – the only happy couple in the film are gay, and the dope-pushing voyeur next door is the only character who knows what he wants and knows how to get it. Kevin Spacey's decision to get out of the corporate life by blackmailing his bosses is clearly pointed up as the right one, and his life is transformed for the better. This liberalism seems rather hard to reconcile with some pretty brutal views of women. The most obvious target is the female lead (Annette Bening), an estate agent who has an affair with a commercial rival whose only attraction is his financial success. Their scenes together are always comic, especially the sex.

For its acting, its look, and above all its writing, this is an exceptional film. Its success is illustrated by the extent to which whole scenes live in the memory, and like a great play it only improves with repeated viewing.

*Frank Minns*

### **Practical Genetics for Primary Care**

**Peter Rose and Anneke Lucassen**

Oxford General Practice Series, 1999

Oxford University Press

PB, 371pp, £32.50, 0 19 262931 X

Having been searching for several years for a suitable text to guide genetics services in primary care, it is a pleasure at last to recognise this book as amply fulfilling the requirements.

Rose is a general practitioner and Lucassen a consultant in clinical genetics. Although billed as joint authors this is really a multi-author book. Each is responsible for his/her own chapters and there are two other authors.

The text is clear and the emphasis is on the practical problems likely to be encountered. There is a generous quotation of case histories, often accompanied by corresponding family pedigrees. Excellent patient information sheets are reproduced. There are numerous tables supplementing and summarising the text. The appendices include information on all the regional genetics centres, genetic sites on the internet and a glossary of genetic terms.

The section on what is called Basic Genetics is less inspiring than it might be. The mechanisms which control the replication of chromosomes and their DNA are fascinatingly complex yet molecularly logical. Lucassen provides all the necessary information but if you seek a true insight I recommend reading *The Book of Man* by Walter Bodmer and Robin McKie.

From then on it is admiration all the way. I can mention only a few important examples. We are guided through taking a family history, including the construction of a family pedigree. Peter Rose emphasises that the counselling skills required by all general practitioners need only minor modification to accommodate the requirements of genetics. There is a very fine chapter on familial cancers by Anneke Lucassen. The discussion of breast cancer is outstanding, making it clear that the majority of patients and their doctors, worried by the patient's family history, greatly exaggerate the risk to the patient. Because this is such a commonly presenting problem, the potential for reducing unnecessary anxiety and the avoidance of unnecessary referrals is vast. I would like to see this section published as a separate booklet and distributed to all practices.

There is a useful chapter on ethical issues. The problem unique to genetics, that any test on an individual almost always has important implications for other family

members, is rightly emphasised. This is particularly difficult, indeed probably insoluble, if relatives have explicitly stated that they do not want to know. There is a fine chapter on the patient's perspective contributed by Aamra Darr, a member of the lay Genetic Interest Group. And of course there is much more. I can enthusiastically recommend this book.

While the authors are to be highly congratulated, the publishers deserve a sharp rap over the knuckles. There are many incorrect word substitutions which are the hallmark of too great a reliance on computer spell checkers. Fetus is spelled in two different ways on two successive pages. There are many summary boxes, which is fine, but not if they are poorly placed so that they spread over more than one page. Understandably, there are many cross references in the text to other chapters. Yet the chapter number is not carried forward as a running heading to each page so that the reader has to go back to the contents page to find the desired chapter. Finally – the ultimate disgrace – in my copy of the book 30 pages were duplicated and 30 pages were missing.

*Clifford Kay*

### **Involving Patients and the Public**

**How to do it better**

**Ruth Chambers**

Radcliffe Medical Press, Oxford 2000

PB, 183pp, £17.95 (1 85775393 3)

As an architect, I have spent my career working on Urban Renewal Projects in Glasgow. As I gained experience it became clear to me that the improvements taking place will only be successful, when the residents are involved at all levels in the decision-making process. Redeveloping communities blossomed when the local residents were allowed to become involved as partners in the process. Ruth Chambers, comes to similar conclusions from a GP perspective, quoting community development work in Newcastle upon Tyne. She demonstrates how primary care practitioners came to regard the community as key asset in creating solutions and became responsive to the community's view. The question on the mind of the NHS and my Local Health Co-ops (LHCC) is how to Achieve a meaningful dialogue with patients and the general public. This paperback is topical and, as I am working with my LHCC on a method to involve the public, I read it looking for real answers and solutions.

*Involving Patients and the Public — How to do it better* is well laid out and an easy read for the health care professional looking for

practical, but well researched options on how best to involve the public. The various exercises have associated examples of how the technique proposed was useful in particular circumstances, with the necessary references at the end of each chapter. Rather than reinventing the wheel, it is essential to be able to choose a method of consultation appropriate to the purpose and available resources. To avoid tokenism the patients or community group should be carefully targeted and appropriate methods used to obtain the information or to enable partnership working. Ruth Chambers advises at the start: Take stock why do it at all? I consider this to be good advice as it is fundamental to know why the involvement exercise proposed is to be carried out and a strategy planned accordingly. Greater patient involvement in the choices and planning of their healthcare will be demanded in the future, health care professionals have a duty to examine the appropriate techniques to make patient involvement central and meaningful.

I have found the book very valuable and informative and will use the methods described to involve the public in the exciting prospect of improving the NHS, and providing health gain.

Ruth Chambers states: There is some evidence that well-informed patients who actively share in decisions about treatment have more favourable health outcomes surely this prospect is worth pursuing.

*Tom Reilly*

#### **Demanding Patients?**

#### **Analysing the Use of Primary Care**

**A Rogers, K Hassell and G Nicholaas**

Open University Press, Buckingham, 1999. PB, 259pp. [price] 0 33520090 7

The question mark in the title of this book sets the tone for a far-ranging discussion which problematises the concept of patient demands in other words, it casts a critical eye over both professional views (including clinical models of need) and social science models which seek to explain the gap between symptoms and service use. Rogers *et al* employ a broad definition of primary care, that includes community pharmacists and complementary therapies, as well as informal, or lay, networks, thus reflecting the everyday concerns and contexts of people's involvement in health and health care (page 26).

One of the important achievements of this volume is its capacity to speak to GPs personal experience, acknowledging the resonance of the heartsink patient, while examining GPs own role in creating demand. I particularly liked the section that

examines the prominence accorded to symptoms (pages 55-59). The distinction between clinical icebergs and icebergs of morbidity is clearly explained and is helpful in explaining apparently conflicting arguments. This chapter also presents a thoughtful discussion of the role of comorbidity and the chronic illness career which may involve patients accommodating to symptoms with a resultant decrease in consultations.

The ensuing discussion, which draws usefully on the authors own empirical research, provides compelling evidence of the importance of patient action and views in understanding the complexities involved in help-seeking and health care utilisation. The authors call for a reappraisal of policy and practice responses, arguing that we need to move on from analysing need to developing strategies to deal with it which take account of the diversity and complexity of patient action (for different groups and at different points in people's lives); the importance of organisational factors and social resources (including patients circumstances and the availability of both lay and professional networks). While Rogers *et al* are optimistic about the potential of PCGs and Trusts, NHS Direct and Health Action Zones to develop more responsive services, they acknowledge the challenges associated with such changes to the culture of health care and recognise the professional and organisational barriers that are likely to constrain new developments.

The authors provide very useful summaries of research findings in a number of important areas, such as patterns of GP consultations and use of community pharmacies, and the book will thus also serve as a valuable resource for those involved in teaching and research. Nevertheless, the layout of the book, in places, strikes me as somewhat arbitrary; for example, the separation of the chapter on Lay action and the formulation of demand into sections on how the experience of illness and service use shapes help-seeking; the influence of individuals action and social networks on help-seeking; and self- and lay-care in managing illness. There is a detailed breakdown of contents that somehow manages not to be self-explanatory; this could prove to be a difficult book to dip into.

Although, as a fellow sociologist, I was comfortable with the terminology used, I suspect that the use of terms such as discourses and the description of definitions of need as contested might irritate or confuse practitioners in equal measure.

*Rosaline Barbour*

*Tom Reilly*

#### *Magnolia*

**PT Anderson, Cert R**

*Magnolia* is a sometimes bizarre, interwoven piece of film-making that is ultimately about chance, but also throws light onto North American culture. At over three hours long it is certainly an accomplished film, as anticipated by the pundits on the basis of the director's previous film, *Boogie Nights*.

In essence there are several story-lines, each intersected by another *a la* John Altman in *Short Cuts*. The setting is 24 hours in Los Angeles and the lives of two dying men and their families, the members of which are either seemingly close or estranged. The human condition is portrayed in various states of emotional turmoil. At the centre is Earl Partridge (Jason Robards), a once-famous television producer, now literally on his death-bed and struggling against pain, regret, and thoughts of his son, whom he has not seen for five years. The latter is Frank Mackey (an unlikely Tom Cruise), a lecherous, combative, evangelical misogynist who almost gets his comeuppance with a female TV interviewer. He is sheer magic a malevolent Southern State preacher on heat would be a fair description in his attempts to persuade the male audience on how to fake being nice and caring and more. Frightening stuff.

In addition, Partridge's wife (Julianne Moore), who freely admits that she cheated on him and married for money, now realises she loves him. Her self-loathing is real and immediate and sends her to the edge.

Another TV man, Jimmy Gator (Philip Baker Hall), a compère of child-versus-adult knowledge game-shows, faces his impending death alone. His misdemeanour is in possibly molesting his own daughter (Melora Walters). She is addicted to cocaine and, in yet another portion of film, agrees to go out on a date with a Christian cop from the LAPD (John C Reilly). He has a heart of gold but is apt to lose important equipment like his gun during a chase. Other characters include William Macey as a down-and-out salesman and closet homosexual who needs to keep working for corrective oral surgery that he doesn't need (wasn't he brilliant in *Fargo*?).

The film does not have the overall coherence of *Short Cuts* and is surreal in places especially the singing episode. But the *dénouement* is absolutely unique and one leaves the cinema in a state of utter shock. Anderson's use of a film-score that almost drowns out the dialogue as in his previous film is odd since the dialogue is key. Three Oscar nominations? Go see, and judge for yourself.

*Surinder Singh*



**General Practitioners in Nottinghamshire (1948-1998): A Health Service Record edited by C Locke**

Nottinghamshire Local Medical Committees Nottingham, 1999  
0 95356560 2

This is a fascinating short book that would be of interest to most GPs practising in the UK. Nine GPs and two administrators give their perspectives on different aspects of working in the NHS during its first fifty years. I found the pieces from the retired GPs particularly interesting. Given the current problems with recruitment in general practice it seems incredible how difficult it was for young GPs to find a partnership in the early days of the NHS. Several of the GPs in this book comment on how fortunate they were to become principals even though they were to be working in areas of high social deprivation and with conditions like seven years to parity. Reading these accounts was a humbling experience for me and the book provides tribute to the tremendous commitment and hard work that has brought general practice to its current state of being.

Other interesting chapters came from an inner-city GP who came to the UK from India in 1968; a GP politician and a female GP balancing the priorities of career and a family.

Although this book is based on Nottinghamshire GPs the accounts would be interesting and relevant to most GPs practising in the UK. I found this an enlightening read and would recommend it to colleagues.

Copies can be obtained on request from the Nottinghamshire LMCs by sending a cheque for £7.50 to Duncan Macmillan House, Porchester Road, Mapperley, Nottingham NG3 6AA (the price includes postage and packing).

*Tony Avery*

## Gratitude

Enjoying work depends on its rewards. It may be rewarding because of its intrinsic interest, or because it is well paid, but the most important reward is being valued. As James Le Fanu and others have recently pointed out, morale among doctors in the United Kingdom has been falling, as is evidenced by recruitment to general practice, early retirement, and failure to pursue a career in medicine.<sup>1</sup> The chief reason for this, according to my thesis, is that is that doctors no longer feel valued, often by management, sometimes by their seniors, but most importantly by their patients.

For those from an older generation, like myself, what made general practice a rewarding career was not being overpaid, not dramatic or life-saving diagnoses, but being thanked. When I started in general practice I was almost without useful therapies but my efforts, useless as most of them were by the criteria of evidence-based medicine, were appreciated and people were grateful for my concern. This appreciation had something to do with the sense that I was a personal doctor and a lot to do with the self-limiting natural history of many of the illnesses about which I was consulted. Christmas was enriched by presents of whiskey and wine, a hand knitted jersey, and much else. After death, relatives often gave pieces, furniture or pictures, as something by which the deceased would be remembered. I am sure that today many of my colleagues are still being so recognised. However, much more important than these physical tokens were the daily rewards of non-verbally expressed gratitude.

How has it come about that doctors are more fearful of being sued than confident that their efforts will be appreciated, especially since modern therapeutics has so much to offer? I am sure that the doctor in a certain famous painting was thanked for his useless vigil. What is certain is that being thanked has little to do with technical competence or skill. Indeed, it is part of experience that effusive thanks are more likely from those which we have mismanaged than from those whom we have managed well.

The need to be appreciated is universal and being appreciated is the key to a happy childhood. At the moment, junior hospital doctors in the NHS are unhappy and are vociferously seeking shorter working hours and more pay. The underlying reason is that they do not feel that their efforts are appreciated, either by patients, by management, or, at least to some extent, by their seniors.

In hospital, patients seldom have a personal relationship with their junior doctors. From the patient's perspective the doctors simply ask questions, make notes, take blood, put up drips and disappear. From the doctor's perspective the demands of the job, the long

hours, and simple fatigue do not allow the possibility of sitting and holding hands.

The lack of appreciation has much to do with the near death of the personal doctor.<sup>2</sup> It has been shown that patients prefer single-handed practices despite the relative lack of ancillary staff, less expensive premises, and sometimes the absence of appointment systems. Such practices are preferred because people are able to identify with a single other person whom they feel is committed to their interest. One of the happy consequences is loyalty.

There is an increasing tendency to believe that transmuted patients into clients or users will make a contribution to reducing the inequality which exists between doctor and patient. This is nonsense because it denies the reality of the subjective experience of illness. Consumers shop around and clients look for value. High street medicine providing impersonal service and convenience fails to meet the needs of those who are ill and fearful. Being ill demands that we find somebody in whom we may place our trust and if we are successful we will, in due course and regardless of the outcome, return.

Gratitude is a gut feeling, satisfaction is intellectual. The unprecedented growth of alternative or complementary therapies may reflect the frequent lack of a personal relationship between physician and patient. The laying on of hands has symbolic meaning and creates intimacy. In so much that many such therapies involve touch, people are comforted by their experience.

Illness and the accompanying inevitable move towards dependency demands more than accurate diagnosis and evidence-based medicine.

Physicians are not judged by their acumen or their intellect, they are judged by their humanity. By relative neglect of the person as a unique and suffering individual the profession is in danger of forfeiting the right to appreciation.

Technical competence and evidence-based medicine are an inadequate response to the human predicament. We are paying a price for the death of the personal doctor. Trust and compassion may stink of paternalism (or maternalism) but without them medicine stinks.<sup>3</sup>

**James McCormick**

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## What is love?

Negative and bitter emotions such as anger, hatred, jealousy, rage, fear, and frustration are commonly encountered in clinical work. But so too are expressions of positive and pleasurable feelings. Joy, happiness, and love can be spontaneously revealed in facial expression and in posture, laughter, gesture and, touch.<sup>1</sup> Patients sometimes assert they are in love or that their partner does not know what love is. They fall in love, become lovesick, and may perceive the effects of love as a drug or pain. These emotional states may even underlie the presenting problem. A recent book, *Love Stories*, has been recommended for anyone with even a passing interest in humanity.<sup>2</sup> But what is love? The question is important since, in the clinical consultation, rational and emotional elements are interwoven;<sup>3</sup> without emotions, we are nothing.<sup>4</sup>

The *Shorter Oxford Dictionary* defines love as: that state of feeling with regard to a person which arises from recognition of attractive qualities, from sympathy, or from natural ties, and manifests itself in warm affection and attachment. But does this definition adequately describe personal experience? To explore this question we undertook a MEDLINE and PsychLIT search. The passionate, romantic, and behavioural aspects of love, its pathologies, love needs, and expressions and treatment of the lovesick have been examined. The approaches are, however, disappointingly prosaic and objective. More enticingly, in the times of the ancient Greeks, Plato distinguished physical from sexual love and introduced his ladder of love in which the love of beauty and truth supersedes physical love. Aristophanes went further and believed love to be the desire to reunite with the lost half of the world and return to the original state of unified joy. Honoré de Balzac believed it to be the poetry of the senses. The Bible, Corinthians 13, speaks poetically of the qualities love has and what it is not. Shakespeare says: Love looks not with the eyes, but with the mind, but later adds Nor hath Love's mind any judgement taste (*Midsummer Night's Dream*, Act I, Scene 1). The evidence of the poets is, however, as conflicting as it is voluminous. Their verses report for example that: Love is heaven and heaven is love; Love is a sickness full of woes; Love is a growing or full constant light; Love is more cruel than lust; Love is not love which alters when it alteration finds; or, more cynically, love begins when you sink in his arms and ends with your arms in the sink!

Children, like adults, can be equally affected by its impact. We sought their views as the spontaneous, imaginative, enthusiastic, and honest expression of children up to the age of 10 years is recognised.<sup>5</sup> Sarah, aged six years, reported that it is something nice inside you; her brother Michael, being a year older, added knowledgeable that it jumps out as a heart. Tom, aged nine years, suggested we were barking mad to even consider the subject

and informed us that football was his first and only love. Lauren, aged 10 years, described love to us as a great big red hot fire inside you that can make you very happy. Our inquiries also revealed that Laura, aged nine years, when asked by her mother how the school day had been, excitedly announced that it had been wonderful, as being there and seeing Johnny, aged 11, had: made my tummy go all funny. To explore possible sex differences, a class of eight- to nine-year old schoolchildren were invited by their teacher to write down comments, thoughts, feelings, and impressions about love. Girls rose happily to the challenge and wrote one or more pages; the boys looked blankly back at the teacher for a full 10 minutes before labouring over one or two sentences, pausing every few minutes to ask: Do I have to do this? Yet among adults it has been reasoned that most of our complex emotional needs can be summarised as the need for love and that men and women each have six unique love needs that are all equally important: men primarily need trust, acceptance, appreciation, admiration, approval, and encouragement; women primarily need caring, understanding, respect, devotion, validation, and reassurance.<sup>6</sup>

So what can we conclude? It seems that the delight, excitement, wonder, pain, pleasure, and enigma of love is intensely personal, highly subjective, and individually manifested. When experienced, adequate definition defies objective expression. Yet life depends on it. Nevertheless, much as they are sought in life, positive, pleasurable feelings and states of being often remain elusive. As Epictetus, a first century Greek philosopher noted: men are disturbed not by things, but the views they take of them. In our times it has been reported that: we clinicians can love our patients and the populations they are part of only when we can comprehend the needs of both, in emotional as well as clinical and epidemiological terms.<sup>7</sup> For these needs, empathy, intuition, support, and directive thinking are important skills to help our patients derive more pleasure from life.<sup>8</sup> They are particularly appreciated by patients.<sup>9</sup> Application of these skills can also lead to greater professional pleasure and our love of clinical practice.<sup>10,11</sup> They are encompassed within the RCGP motto: Cum scientia caritas science with humanity and feeling. However, humanity is a longed for and often elusive quality in medicine.<sup>12</sup> A recent Nuffield Trust Working Group defined it as: the study of human nature and the practice of concern for the advancement of mankind's welfare.<sup>13</sup> Yet it has been reasoned that no medical school can teach a young person how to be understanding and caring. This can come only from the experience of life.<sup>14</sup>

It seems, therefore, that as love can enhance all our lives, it should in all its dimensions be fully explored, appreciated, and enjoyed with our patients.

**Robin Philipp and Ernst Philipp**

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## Awards and Fellowship Committees: activities during 1999

During the past year the Awards Committee concentrated on developing its policies in line with the College's policy on improving transparency and openness with its awards and fellowships. Also, guidelines on discretionary duties of the President have been approved, in respect of the issue of awards/fellowships in exceptional circumstances, such as a terminally ill candidate who might not live in time for his/her award to be ratified at the AGM. Council has agreed that the President can take Chairman's action to award Fellowship or a high award to those doctors whose names have been approved by Council for Fellowship but who are seriously ill.

Improved guidelines on Honorary Fellowship, Membership under Ordinance 3 (c) (previously known as Ordinance 3(d)) and the Kuenssberg Award were also approved by Council during the year. For information on these and any other College awards, please contact Princes Gate.

Council's paper on *Tackling Racial Discrimination* was supported by the Committee. Most College awards by competition are now anonymised to prevent discrimination. It is hoped the increased

openness and transparency with procedures will also help achieve this.

The Committee conducted a survey during the year of the range of awards within the faculties. There is now a full analysis from all replies received and it is hoped this will eventually be published in College Awards. Also, the Committee has prepared a grid of all senior College individuals, other senior national figures, and award winners to ensure that no particular individual is overlooked when considering nominations for awards.

The Fellowship Committee was joined by Dr Patricia Wilkie, Chairman, Patients' Liaison Group as an *ex officio* member; this is the first time in the history of the College that a lay member has joined the Fellowship Committee.

During the year, the Committee concentrated on producing new guidelines for Fellowship by Nomination these are the biggest changes since Fellowship of the College was first established and have been put into effect for the first time with this year's recommendations for Fellowship. These were drawn up following concern expressed in previous years about lack of equity between faculties, secrecy about the process, and an absence of systems to ensure avoidance of discrimination. The new guidelines are based on the principle that criteria and their interpretation for Fellowship should be as objective, measurable, and as transparent as possible and that there should be patient involvement in the process. The Committee supported the recommendations of the Council report *Tackling Racial Discrimination* and will be monitoring the ethnic status of new Fellows from this year.

The Committee, with the Awards Committee, considered a survey of other College's procedures regarding posthumous Awards. It has now produced some procedures for future Chairmen about discretionary duties of the President in the rare case of a terminally ill candidate for Fellowship by nomination. Council has agreed that the College should adopt a compassionate approach to Fellowship and Awards and that it was undesirable for distinguished members to be denied Fellowship or a high award through illness or death after Council had approved their name.

Following its discussion on the new Fellowship procedures, Council has asked the Committee to look at the possibility of separating the awards of Fellowship by Nomination and Fellowship by Assessment. The Committee is reviewing this in relation to the increasing need for patients to have explicit information about the meaning of doctor's qualifications, including Fellowship.





## Red Shoes

I  
'Wear these shoes,  
my love,  
and dance for your Daddy.'

She laughed then,  
clapped her hands.

II  
She wielded so many knives  
in each hand, she became a blur  
of steel, catching and sparking  
blades of light

to chop out laughter,  
singing,  
dancing  
cut by mummy's voice  
'Stop That - Now.  
'It'll end in Tears';

to ward off daddy's hand  
excited  
by her excitement.

III  
Little-girl slippers  
gnaw into woman's flesh:

'Dance to Daddy's tune, my love,  
dance.'

She knows  
the only way for a girl  
to be safe

is to slice  
her self  
from her body.

Only an axe  
at the ankle  
can remove slippers  
buckled to flesh;  
even then, her butchered feet  
in scarlet silk  
will pirouette before her  
every time she tries to laugh.

Now, though she's hobbled  
on wooden feet  
into marriage, motherhood:  
the meat cleaver's still there  
dancing,  
ready.

IV  
She watches the hammer  
jig on the anvil  
to beat that living glow  
right out of the steel:  
takes the tempered blades,

pares Daddy out of her mind,

and hurls the knives  
up and away,  
a blue brightness winking in the sun  
so she can jive -  
feel herself in heart, brain and toes;  
her skirt is a bell  
under outstretched hands,  
her laugh a banner  
of scarlet silk.

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## neville goodman

### Cynicism

People wonder why I'm cynical. One of our trainees asked me, 'Is there anything you've actually liked in the various changes to the NHS?' The answer is that I can't remember any. That's not because there haven't been any good changes, but because there's no point wasting mental energy on good things. I'm a columnist: I prickle; therefore I am. I was shown a newspaper headline, 'Stop moaning!', with the suggestion I should take notice. No chance!

Take last year's government strategy to cut waiting lists. The Waiting List Working Group, a Department of Health-funded body, produced a report containing facts and figures, descriptions and strategies, graphs and flowcharts: a comprehensive document on how waiting lists arise, where blocks occur in the system, and how these blocks can be circumvented or removed. As an example: look at your clinic activity, look for no-shows, look for seasonal variations in these data - is there anything that can be done to increase activity?

The report was a ring-bound, glossy, multi-coloured, A4-sized volume, 21 mm thick and weighing 1.46 kg. Parcel Force, who delivered it, charge £3.55 for that weight. Parcel Force may charge the DoH less than they charge your average punter, but the cost of just publishing, printing, and delivering this tome must be considerable - quite a few hip replacements or cataract removals anyway.

For reasons that escape me, the binding was bottom to top rather than side to side, which made this already large book difficult to handle. To give an idea of the solidity of the contents, page 15 had just two short sentences printed on it, in a coloured box in the centre of a page otherwise blank except for the header and footer. The first sentence read:

*Treatment of patients is a core function of the NHS.*

The government has imposed all sorts of untested grand schemes which they try to convince us will turn the dear old ordinary NHS into something it calls the New NHS. Conspicuous to their ideas is that all this will happen within available resources (give or take a flu epidemic or two). Yet something that could reasonably be produced in a small pamphlet without in any way being 'cheap' is inflated to fill many times the necessary space. What are doctors expected to think of this? Especially when some of the statements made within its pages are either an insult to our intelligence or an indication of theirs.

## our contributors

**Tony Avery** is a GP in Nottingham

**Iain Bamforth** has recently completed a new English translation of *Knock or the Triumph of Medicine*, by Jules Romains (1923), about the medicalisation of a little town in France. Iain is happy to supply a copy to anyone interested in staging it.

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**Tom Reilly** is an architect. He worked in East Kilbride and Cumbernauld New Towns, and, as Principal Architect with Scottish Special Housing Association, on urban renewal in Glasgow and the West of Scotland. He sought to empower residents in planning their own homes and communities. He chairs the RCGP Scottish Patient Liaison Group

**Surinder Singh** is an academic GP in north London and a normal GP in Lewisham, south east London. He is a member of the *Journal* Editorial Board, and is disturbingly fond of Manchester United

*On Genes...*

**John Burn** is Professor of Clinical Genetics at the University of Newcastle upon Tyne and chairs both the British Society for Human Genetics and the UK Cancer Genetics Group. He was instrumental in bringing the new public Gene Centre to Newcastle

**Neva Haites** is an Australian who transplanted to Aberdeen and flourished. Now she is Professor of Genetics and a clinical Dean at Aberdeen Medical School. Since 1991 she has run a clinic for familial cancers for Grampian region. She led the recent multi-centre and highly productive EC Demonstration Programme on Clinical Services for Breast Cancer Families.

**Pål Møller** is Head of Genetics at the Norwegian Radium Hospital in Oslo, providing a service for the whole of Norway. His interests cover many aspects of genetics, including genetic epidemiology and ethics. The bulk of his activity now concerns familial cancers and data from his department on outcomes of screening and cost-effectiveness are among the most comprehensive in the world.

**Michael Steel** is Professor in Medical Science at St Andrews. His clinical interests lie in the clinical and molecular genetics of breast cancer, and geography permits him to participate in weekly cancer family clinics in both Edinburgh and Dundee. He is believed to be the only golfer among the five signatories, though colleagues dispute his claim to that description.

**Tiere Vigen** pronounces on matters genetic on behalf of the Norwegian Medical Association.

## bruce charlton

### Philosophical Confessions

Philosophy: a good or bad thing? Discuss.

Sometimes I see myself as essentially a philosopher at others I see philosophy as an essentially bogus activity. Perhaps these statements are mutually reinforcing?

Take Ludwig Wittgenstein (please). He created an amazing mystique around his own personality and work by continually accusing other people of misunderstanding or misrepresenting him. The few people who gave an accurate account of his views were accused of having stolen them.

I spent four years trying to understand why I was not supposed to be able to understand Wittgenstein. Trying to understand why something that seemed obvious (but mistaken) was supposed to be beyond my comprehension (but true). Once you get enmeshed in this world, it is pretty difficult to find your way out again. Banal utterances are interpreted as profundities which the reader is simply too crass to appreciate, statements that appear idiotic are reframed as further evidence of the reader's lack of moral seriousness. False statements are not wrong, they are deep.

\* \* \*

Philosophy started with aspirations to be the Queen of Sciences – the one route to eternal and objective truth. Well, it hasn't worked out that way. What remains of philosophy, as we stand on the cusp of the twenty-first century, is a mere rump of what has been left behind after the successful disciplines have been subtracted. Stunningly successful branches of knowledge, such as Mathematics, the Natural Sciences, and History, were once parts of philosophy but have now set up shop in their own right. Indeed, as soon as any branch of philosophy starts to make any serious progress, it stops being philosophy. No wonder that philosophy never provides any answers and seems to be going nowhere.

And yet, and yet I still keep reading philosophy. Albeit, the philosophers whom I admire tend to be dismissed by professional philosophers as not doing philosophy: Nietzsche, for example. But then, professional philosophers are just a bunch of people who have a salaried job with the title of philosopher. So who cares what they think?

But, in a way, the professional philosophers are probably right. The best philosophy is not a subject in its own right, not a set of doctrines or assumptions, not a method, nor even an agreed canon of authors. The best philosophy is nothing other than theoretical reflection which springs from practice: thinking about something you care about for longer and harder than other people typically do. (And, to be fair which he never was Wittgenstein said something of this sort somewhere.)

Somewhere in *The Lord of the Rings* JRR Tolkien describes the innkeeper, Barleyman Butterbur, as someone who could see through a wall, if he stared at it long enough. I am continually amazed by the progress that can be made in medicine, in psychology, in politics by carrying on worrying at a problem long after other people have wandered away to do something more useful.

Most philosophers have a sustained power of attention which greatly exceeds that of most doctors or scientists. This sustained attention is supported by the structures of philosophical discourse, that allow much more time, more conversation, longer articles, longer books. All this may enable philosophers to make progress when they apply their attention to subjects about which they also have substantive knowledge: as with Alasdair MacIntyre's reflections on the ethical basis of managerialism (or rather, the lack of it), David Hull's work in evolutionary theory, or George Elder Davie's books on Universities.

\* \* \*

So, in the end, I like philosophy because it is the antithesis of busyness. Most of the best work I have done (such as it is) was achieved by staring at a problem until I could see through it – even when this process took 20 years, as in the case of understanding psychiatric depression. Research is not confined to the lab or the clinic but necessarily involves sitting in armchairs, lying in the bath, and jotting notes as I walk.

Philosophy is the child of idleness. Which explains why I *am* a philosopher, after all.