

DEMOCRATIZE OR PERISH: HEALTH SCIENCES AS A PATH FOR SOCIAL CHANGE

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SINCE THE 1970s we have entered an era of paradox. Not since the 1930s has there been so wide a consensus that capitalism is fundamentally flawed, in its apparently uncontrollable pursuit of profit, regardless of human needs. Yet never has there been such universal despair of any feasible alternative. We don't need more books to prove the moral and cultural bankruptcy of capitalism, its obscene contrasts between human and market priorities, or the growing instability and mutual violence of a society forcing everyone to act only for themselves. We need a credible alternative.

Before 1917, a variety of alternative projects seemed credible because they had never been tried. October 1917 opened a real, material, fighting alternative to mutual annihilation in the trenches, with prospects so dazzling that selective blindness came easily. Though it was soon clear we could not have what we liked, either in the revolutionary East or the reforming West, we learned to like what we had as the price for any action at all. The 1917 revolution, and others following its model, led to an abyss. They were paths out of feudal autocracy and colonialism, but they were not paths to socialism as a way of organizing a more advanced society, including and surpassing all the real achievements of capitalism. So we are rightly cautious of all other alternatives so far on offer, particularly if they seem in any way to resemble revolutionary socialism. Having lost material hope for the future, millions of desperate people now turn to past superstitions as their only apparent alternatives to the inhuman world of the market.

Marx and Engels believed that each stage in evolving society creates its own

gravediggers. More relevantly to our predicament, they believed that the builders of each new society were developed by the old, workers who were necessarily in conflict with it – because their new mode of production required new social relations, new divisions of labour, of power, and of property – but who were also essential to its continued development. They saw labourers, stripped of all productive property other than their own labour power, as the revolutionary class. Evolving capitalist production would simplify social divisions, until a diminishing number of owners of the means of production would face a growing majority of workers, whose interests required collective ownership and control, and who were able to understand production motivated by human needs rather than profit and expanded capital.

All this seems easily recognisable today – easier than at any time since 1848. At the heart of modern capitalism lies production of knowledge. Its ultimate products remain commodities, produced not because they are needed but because they are profitable, but its immediate and most important products are all different kinds of new knowledge. Trade in labour power as manual labour, even as highly skilled use of machines, is now being displaced by trade in intellectual skills – above all, by the capacity to learn. This has huge implications for the nature of production, and the social relations required by production.

In this essay, focusing on the production of health care, I hope to show that this new kind of production can't operate efficiently without creating new social relationships – and therefore new kinds of people – ultimately inimical to capitalist society, yet essential to its continued expansion. These new people will be a new and much more powerful army of gravediggers for the old society, but more importantly, they will be more imaginative and better informed builders of a new society. They will show that there *is* a feasible alternative, working better in every way than the old. They will bring huge reinforcements to an old labour movement which has not in fact disappeared, adding immense new power – the advent of truly scientific socialists, able to deal confidently with the world as it actually is, without recourse to romance.

A PRACTICAL EXAMPLE

How good medicine – genuinely scientific medicine – points firmly in the direction of a new kind of socialist society is exemplified in a new project now being developed in Wales. The south Wales valleys hold a quarter of the Welsh population, about seven hundred thousand people. Adding Swansea and Port Talbot, which resemble the valleys in their dependence on mostly collapsed heavy industry and were part of the coalfield at its peak of production before World War I, the population approaches a million. Its social problems closely resemble those throughout the world, wherever industrial commodity production is already exhausted, manual skills are no longer needed, and entire communities have ceased to be profitable for the owners of capital.

The south Wales valleys contain more poverty, hopelessness, and ill health than any other area in England or Wales of like size, the consequences of

economic deconstruction and decline. For the past fifty years, it has been increasingly hard to recruit family doctors (General Practitioners, or GPs) to deal with these health problems, and their work has appeared increasingly futile, mainly because the causes of ill health are growing faster than either actual or even any possible medical remedies, since social conditions are undermining young people's will to live. Many GPs are therefore looking forward to early retirement and they will be replaced either by colleagues who can't find work anywhere else, or not at all. Even to maintain the barely adequate service the valleys now have, this impending crisis in recruitment must somehow be solved during the next decade. This will not be possible if central responsibility for primary care remains with GPs working as self-employed small businessmen, as they still are.

To respond to this a ten-year plan has been developed by the Socialist Health Association, *Going For Gold*, based on the valleys' history, culture, labour, and potential advantages for investment. It depends on four integrated themes: health care, education, research and employment.

Initial and continuing health care will be provided through a salaried primary medical and nursing service. Private ownership and administration by general practitioners as independently contracted small businessmen will be gradually and voluntarily phased out. It will be replaced by team care, with important roles for nurse-practitioners as well as for doctors. Teams will work from health centres, which will also offer dental and pharmaceutical services. They will build their work around anticipatory care of long-term health problems, intervening at an earlier stage in cascading misfortune than hitherto, reducing presently escalating demands for crisis and emergency care.

Education will be developed at two levels. First, mature adults with personal experience of chronic illness (for example, diabetes, epilepsy, or tobacco-related disorders) will be recruited locally to provide a range of specialized continuing anticipatory care and advice of a non-technical kind within primary care teams, as Chronic Problem Advisers (CPAs). After a brief introductory course, their higher professional training will depend on continued in-service learning and team development, based on extramural departments of the universities of Glamorgan and Swansea. Second, primary and secondary schools will develop local programmes to base science in the national curriculum on local health and health care data, aiming to shift popular perception of health sciences and health care to biological rather than engineering models, and raise learning to levels required for skilled biotechnical employment.

As for research, the third arm of the plan, the Rhondda Fach in south Wales was, as it happens, the birthplace of epidemiological research in the post-war world. This research extended the study of human health, health problems and health care beyond laboratories and hospitals, into real populations as they actually live and work. Important preconditions for this were the birth of the NHS itself, and the social attitudes and expectations associated with it, plus active support and co-operation from the then very powerful community network of

the National Union of Mineworkers. Salaried primary care teams, supported by modern information technology, if combined with renewed social solidarity of the sort which gave birth to the NHS and gave trades unionism such deep roots in the valleys, offer exceptional potential for mass participation in research. As is shown below, this is needed to make health care more effective, efficient, and relevant to public health, and to advance fundamental biomedical knowledge, creating new weapons to promote health, and prevent or treat disease. Participation in research also has immense learning potential, both for those who organize it, and those who become research subjects.

In terms of employment, community participation in research, and rising standards of education producing potential skilled workers in biotechnology, could be integrated in a Valleys Health Sciences Industrial Park, attracting inward investment by pharmaceutical and other biotechnical industries. Together with greatly expanded, labour-intensive NHS primary care, this could make work in health care, health sciences, and health-related products a new staple employment comparable in scale with coal, steel, tinplate and other heavy industries in the past.

The valley communities developed collective bargaining to agree the terms on which they made their labour available to extract coal.¹ The valley communities today could develop collective bargaining to agree terms on which they would participate in creating and using new biotechnical knowledge. Only after collective agreement could researchers recruit individual participants. Payments for participation (other than refunding of expenses) would go to participating communities rather than individuals, by transfers from biomedical companies to schools, health and social services, or to other agreed community agencies. The chief gain and incentive for communities would be skilled, diverse, stable employment, retaining young people with higher education rather than exporting them, and eventually reversing population outflow.

This approach could restore hope, reverse depopulation, and end economic and social dereliction and dependency. Such social changes would have more powerful effects on health than any improvements in the quality and quantity of NHS care, necessary and important though these are. It is not an easy solution, but what solutions are? The plan, developed over two years, is already backed by three rival universities (academics will know how hard that is to achieve), by Welsh Assembly health minister Jane Hutt, by senior civil servants at the Welsh Office, and by health service unions UNISON, MSF and the BMA. It has an office, an executive team, and pilot sites to be set up in 1999. Most importantly, key figures among established local GPs endorse this plan as a broad framework within which primary care should develop.

Of course it is impossible to tell whether this strategy will succeed in these particular circumstances, though they are in many ways favourable. But I am fairly sure something very like it will succeed sooner or later, somewhere in the more exhausted parts of the industrialized world, and my reasons for thinking this go to the heart of the issues raised by Marx's and Engels' analysis. These

reasons can best be explained by first looking briefly at the British National Health Service as it was originally conceived.

THE NATIONAL HEALTH SERVICE AS AUTHORITARIAN SOCIALISM

The NHS was launched in 1948, in my first year of clinical studies. It nationalized virtually the entire health care industry, then generally understood as having two main functions: cure (episodic repairs) for the relatively few problems that seemed curable, and care (continuing support) for the large majority of problems that seemed either self-limiting, or incurable. Prevention was seen as a subordinate activity, already separated from both caring and curing. Despite much unifying rhetoric and occasional steps toward unified practice, this separate view of prevention still persists.

The NHS almost entirely took over the production of what had hitherto been an extremely popular traded commodity, personal health care, previously supplied by doctors as self-employed entrepreneurs. It made an important and valued service available to everyone free. The main reason this zero-priced commodity did not generate infinite demand (contrary to educated expectation and later received wisdom) was that most people intuitively understood that medical care worked better as a social gift than as a traded commodity. Like its antecedents in workers' mutual aid societies, well people paid taxes throughout their lives to help sick people, for a service they hoped never to need themselves. Once people had experience of prepaid care, free at time of need, the concept of care as a human right rather than a commodity, and of a medical profession with a duty to provide continuing care rather than the episodic sale of body repairs, became rooted in British popular culture.

For thirty years, from 1948 to 1979, medical care virtually ceased to be regarded as a commodity, either by the public or by professionals. Though some private practice persisted for hospital specialists, particularly for surgeons, and this had important effects on the number of consultants, on consultant culture, and on NHS efficiency,² private medicine lost its moral authority, particularly in the medical schools. When Margaret Thatcher imposed market concepts on the NHS after 1979, she found her 'reforms' opposed by all organized health professionals, by doctors as much as by other health workers. This was a complete reversal of the situation in 1948. Doctors had learned, through personal experience, that they had more scope, greater security and more job satisfaction as public servants serving human needs than as private salesmen of medical care.

The NHS applied the principle 'from all according to their abilities, to all according to their needs', without cash transactions or profit. Contrary to all received economic wisdom, this produced a service costing several times less than marketed care in USA, though of roughly equivalent average clinical standard,³ at least until the 1980s.⁴ It presented an extremely popular, relatively cost-effective service compared with marketed health care systems.

However, though the face of the NHS was seldom inhuman, it was generally authoritarian. Most doctors were as ignorant of the real constraints of most people's daily lives as most patients were of the nature of clinical decisions. Apart from an important element of central planning to rationalize the geographical distribution of resources, for its first thirty years the NHS was run by doctors, virtually without lay control. They believed they ran the service primarily in the interests of patients rather than themselves, but in this respect they proved neither better nor worse than other professionals, all of whom shared the squire's traditional concern for, but ignorance of, his tenants. The resources of the NHS were in the personal gift of its doctors, in conditions of permanent scarcity of resources (depending as they did on a redistributive income tax which the right wing was determined to undo).

The right also understood that many patients could be induced to prefer being valued as customers to being objects of increasingly threadbare medical charity. From 1979 to 1997 the socialist principles of the NHS came under sustained assault from Conservative governments determined to remould every aspect of British society in the image of competitive small enterprise, while government itself concentrated power at the centre like a large corporation. The NHS, with its roots in popular culture and in a slowly democratizing new professional culture, was the largest and most stubborn obstacle to this remoulding process; but huge inroads were made into it, with immense damage to staff morale and traditions of public service, a rapid and extremely costly rise in litigation, and relentlessly rising demand, as patients were officially encouraged to expect more while resources were simultaneously reduced.

RELATIONS OF PRODUCTION IN HEALTH CARE

But these trends were and are in contradiction with a growing realisation among health practitioners that truly science-based medicine points in a quite different direction; and in spite of the pressures to 'marketize' the NHS there has also been continued growth in the idea of participative democracy in health care, with patients and professionals developing new roles as co-producers of health rather than as opposed consumers and providers of health care.⁵ The aim is not to maximize profits but to increase public health – healthier births, healthier lives, and healthier deaths. To achieve this, democratic social relations are fundamental, for reasons that need to be made clear.

The first key elements in processes of clinical production are decisions about whether patients' problems really call for health care, and if so, what interventions are most likely to assist their solution. Clinical interventions themselves are essentially subordinate to these decisions. If a patient has problems which can't be solved by taking out her appendix, gall bladder or uterus, then however well these procedures may be performed, they will reduce efficiency (however it is measured), besides causing occasional operative deaths. Yet the relation between scientific knowledge and clinical practice is still extremely variable. Rates for these common surgical procedures (and for their occasional compli-

cations) show huge variability between countries, within countries, and even between localities with similar age distributions and social structures, and little relation to the statistical prevalence of the conditions for which the procedures are appropriate.⁶ For tonsillectomy, for example, we still have no good controlled evidence that it is effective, though it is still the commonest surgical procedure in childhood. At best, the evidence suggests it may on average prevent about two moderate or severe episodes of sore throat in the two years following the operation.⁷

NHS doctors are moving toward evidence-based decisions, and doing so faster than their colleagues in marketed systems. There, surgical intervention rates are grossly inflated because the pursuit of profit rewards credulity and penalizes scepticism. Children in fee-driven US practice are eight times more likely to have a tonsillectomy than children in the fees-free NHS, while a study of coronary bypass surgery in USA showed that 22% of grafted patients had no symptoms of coronary disease, and had evidently been persuaded to undergo surgery on questionable evidence.⁸ At the same time, poor people who needed surgery weren't getting it.⁹

But even without such perverse incentives clinicians in the NHS do still commonly fail to consider the full range of evidence needed for optimal decisions. Hasty decisions to intervene are still made when surgery is irrelevant to patients' real problems,¹⁰ and poor people are still under-referred for interventions they need.¹¹ A similar wide variation is found in most diagnostic and treatment decisions. Public attention tends to concentrate on the quality of interventions, rather than on the quality of the preceding decisions, first on whether to intervene at all, and secondly on which intervention to choose. As the main scope for efficiency gains lies in making practice evidence-based and rational, this issue is central to the development of an affordable health service.¹²

WHAT COUNTS AS CLINICAL EVIDENCE IN SCIENTIFIC HEALTH CARE?

The quality of clinical decisions depends on the range and quality of evidence used to make them. This evidence is conventionally seen as coming from accumulated professional knowledge. Experienced doctors are said to use about two million pieces of information in reaching their decisions. The doubling time of the biomedical knowledge base is currently about nineteen years, so it increases about fourfold in a professional lifetime.¹³ Simply to keep up with advances in general internal medicine, a doctor would need to read 19 articles each day, 365 days a year. But self-reported time spent in such reading averages well under one hour weekly for British medical specialists, or two hours for medical teachers. Actual times are probably less, and less still for GPs.¹⁴ This gap has led to the centralized collection, analysis, evaluation and eventually (still unsystematic) distribution of new information from all over the world,¹⁵ in a generally laudable movement toward 'evidence-based practice'.

Evidence-based practice is, then, necessary and long overdue, but what kinds

of evidence should it include? Health professionals and patients have different perceptions of what seems most useful for clinical decisions and what patients want is seldom exactly what clinicians think they need.¹⁶ But the main determinant of successful output from consultations is agreement between doctors and patients about the main problems presented. Improved teaching and resourcing can raise agreement between doctors and patients on the nature of the main problems to roughly 80% in teaching centres, but for most patients little has changed and agreement is much lower elsewhere.¹⁷ In the USA in the late 1970s, Barbara Starfield found doctors and patients agreed on this in only about half of all visits.¹⁸ Another study found that in consultations for bodily complaints, doctors and patients agreed on the nature of main problems in 75% of cases, but for those mainly concerning the mind, agreement fell to 6%.¹⁹ Beckman found that doctors allowed patients an average of eighteen seconds to tell their story before interrupting and diverting them to doctor-preferred topics.²⁰ In Canada, McWhinney found 54% of patients' complaints and 45% of their concerns were not being elicited.²¹

The consequences can be stark. An audit of records for elderly London nursing home residents showed no medical information in 40%, no social information in 70%, and no nursing information in 30%.²² And over one-third of them were found definitely to need home or residential care rather than nursing home care. They had been put in the wrong place, at an estimated lifetime added cost per misplaced resident of £42,250. 82% of these residents had been sent into long-term care from acute hospitals, so these decisions had been taken by health professionals.²³

In general, all professionals are educated to see themselves as guardians of society, floodgate-keepers against potentially infinite demand on finite resources, whether in the NHS or any other social services. In reality, the opposite is more often true. Another study found only a quarter of residents in private nursing homes had been given any choice over where they went, and institutional care of any kind is in fact a last resort for the immense majority of people with a family member in need of care. The 'floodgates' idea is based on ignorance of the sociology of family relationships and, particularly, of reciprocity between generations. It insults millions of caring relatives.²⁴ It is another example of what happens when professionals take decisions, applying only their own narrow range of evidence and an unchallenged set of social assumptions, while ignoring evidence from patients and their families.

For health professionals and patients to relate to each other as co-producers rather than as providers and consumers, decisions must draw from both sources of evidence. If experienced health professionals have specific local knowledge not included in the general knowledge base, we need this too. Evidence-based practice must become an exercise in participative democracy, with evidence from patients valued equally with evidence from health professionals, and evidence from local experience valued equally with evidence from the academic knowledge base.²⁵ A shift in this direction has continued at an accelerating

pace throughout my lifetime, though progress always seems painfully slow. In the early '80s even doctors who prided themselves on their patient-centred consultations were found to be ignoring patients' own ideas about their problems.²⁶ Since then there has been solid progress, even though the time constraints and bad habits formed by under-resourced and narrowly conceived care make this difficult.²⁷ But at least the currently dominant concept of good practice now places patients, and the evidence they bring, at the same level as health professionals.²⁸

Among health policy-makers, the currently prevailing doctrine works against this. Economists and policy consultants demand that health professionals abandon their traditional responsibility as advocates for their patients and become instead agents of 'value-for-money' management and rationers of dwindling public services.²⁹ But very few people who are actually responsible for patient care will follow this suicidal policy. If patients lose confidence that their personal health advisers think and act in their personal interest, professionals will lose the immense gains in public standing and self-esteem they have made since 1948. They will lose their credibility as advisers *against* costly interventions that are likely to be futile or damaging, as well as their credibility as determined advocates on patients' behalf when they do need care, however costly. If public confidence in such independent judgements were lost, clinical decisions would face the full force of consumerism, with catastrophic consequences for an affordable NHS. Doctors would be mistrusted, litigation would escalate, patients would feel they must constantly try to 'get' as much health care as they could. The total cost of health care would rise while the health gain per pound spent would fall, just as it has in the USA.

Instead, the general direction clinical medicine must take involves the development of patients and their informal carers as co-producers of health rather than consumers of care. Respect for their evidence must come to be seen as no less necessary to accurate clinical decisions than the collective experience of medicine in the scientific literature, or the personal experience of clinicians. The speed of advance may be doubtful, because it depends on active struggle and argument, but of the aim we need have no doubts at all: scientific medicine must democratize or perish.

THE DEMOCRATIC BASIS OF CLINICAL RESEARCH

What is true for clinical relationships is equally true for research. Less than half of all treatments now in common use have ever been evaluated with the rigour that randomized controlled trials alone can make possible.³⁰ For all these treatments, the balance between health gain and collateral damage remains unknown. We should not assume this balance is positive, merely because we wish it so. Take hormone replacement therapy (HRT), for example. Despite billions of prescriptions, millions of tons of promotional newsprint, huge profits and reckless endorsement by numerous ageproof celebrities, HRT still rests on optimistic assumptions, not controlled evidence. There's room for some nasty

shocks. The Medical Research Council (MRC) in Britain plans to recruit 34,000 women internationally for a randomized trial measuring the effects of HRT on coronary heart disease, stroke, fractures, breast cancer, Alzheimer's disease and autoimmune disease, as well as control of menopausal symptoms.³¹

This fundamental method in medical research is largely due to the work of the pioneering epidemiologist Archie Cochrane who, working initially in south Wales in the 1950s, was the first to recognize the importance and feasibility of studying virtually whole populations, rather than the compliant but unrepresentative subsets most readily available. He drew on wartime experience of operations research,³² applying methods of experimental science to commonplace diagnostic and treatment decisions and interventions. His crusade to base medical practice on evidence from randomized controlled trials met stiff resistance for about thirty years, but eventually the idea was rapidly assimilated into established wisdom. Now, trials for important treatments may require hundreds of thousands of participants observed over many years: by 1996 the British Medical Research Council's General Practice Research Framework included 6,490,000 people, 11% of the whole UK population.³³

In 1961, after acquiring some elementary research skills while apprenticed to Cochrane, I returned to practice in Glyncoerrwg, a coal-mining village not far from the Rhondda Fach where Cochrane's studies began in 1949.³⁴ In this small unit, serving about two thousand people, our doctor/nurse team developed a new style of work combining reactive care (traditional response to patient's presented complaints) with proactive care (active, systematic search for health needs). This entailed moving from a sole concern with episodes of sickness to a longer-term view of continuing health and illness. Improved clinical decisions depended on accumulating information in the form of life stories in what were then exceptionally comprehensive records, so that a wider range and better quality of evidence was available. On this basis we developed a system of *anticipatory care*, intervening at a much earlier stage in the cumulative and accelerating cascades of misfortune that lead to gross symptomatic disease.

This system, combining public health ideas of prevention with clinical medicine, was effective and efficient. With a small team giving patients roughly twice as much consultation time as the average general practice, and using much better records, age-standardized death rates were reduced over twenty-five years by roughly 28% in Glyncoerrwg, compared with a neighbouring community with high quality but traditional care.³⁵ The data base created and maintained for anticipatory care of this registered, enumerated and defined population also provided the basic requirements for high quality epidemiological research. From 1968, first alone and later assisted by the MRC, the Glyncoerrwg Unit produced a stream of publications in the major medical journals.³⁶

Medical knowledge at the close of the twentieth century depends on many different levels of enquiry, not only in laboratories or hospital wards, but also where people live, work, and lead their lives. Effective methods of treatment rarely begin from unequivocal breakthroughs. In the early stages of innovation,

significant differences between the outcomes of new and old treatments are usually marginal. For example, when I began work in 1952, childhood leukaemia was always fatal within a few months. By the late 1950s, new methods of treatment were prolonging life beyond a year in about 80% of cases, but after this brief reprieve they all died. Today, over 80% of children with leukaemia are cured permanently. Development of effective treatment depended on a long series of double-blind, randomized controlled trials. Where we had no good evidence on which to base a choice between an established treatment and a new treatment, we asked parents and children to help us find that evidence, by participating in trials in which patients were allocated randomly to one of the treatments in question. Results were not biased by the hopes and expectations of either doctors or patients, because neither of them knew till the end of the trial to which group each patient belonged.

The results of such trials are produced not only by researchers in basic sciences or innovative clinical specialists who formulate research questions, but also by patients who participate. Though their participation is clearly essential, it has hitherto been regarded as essentially passive, in the same way as patients were perceived as passive consumers in diagnosis and treatment. This is not so.

AN 'IMPOSSIBLE' TRIAL

The mostly unappreciated creative potential of trial participants is easier to see if we consider a case from my own experience, the MRC Thrombosis Prevention Trial (TPT) of low-dose warfarin and aspirin.³⁷ This entailed first, identifying men aged 45–64 in the top 20% of risk for coronary thrombosis. Then we asked them to accept randomization either to warfarin (rat poison) or a placebo, and blood sampling from their veins every three months for the next twelve years. When we began, there was a small but unknown risk of provoking bleeding. Experience showed this hardly ever happened at the doses we used, but that's hindsight. So great were the demands we made on trial participants that when we, and one other practice in England, first undertook the pilot studies for this project (later extended to over a hundred practices throughout the UK), the main question we had to answer was not how to organize it, but whether any such trial was feasible. In fact 82% of men in our target age group agreed to screening for categorization of risk, and 87% of those identified in the top 20% of risk had entered and stayed in the randomized treatment phase 18 months later. The overall UK response rate for screening was lower at 66%, and 52% of men in that top 20% of risk entered the randomized treatment phase. The trial ended in 1997, after 40,000 man-years of experience.

What did all this achieve? Treatment reduced all coronary heart attacks by about one-third (35%), and death rates for all causes by 17%. Strokes increased slightly, but treatment prevented about six heart attacks for each additional stroke. As in most scientific research, the new knowledge gained was complex, and harder to apply in practice than newspapers and television reporters wanted, but useful knowledge was gained which will improve patient care when fully applied.

Why did our participants and their communities take part in all these trials and research studies? Why should women agree to take part in HRT trials for a treatment already in widespread use? Why should mature men, knowing they were at high coronary risk, spend twelve years randomized either to rat poison or a placebo (neither they nor their doctors knowing which) and being bled every three months? These are serious questions. If we want rational and effective treatment, trials are essential on a mass scale. On what basis can we expect people to take part in them?

According to philosophizers of the Third Way, better education and rising consumption are associated with reduced social solidarity. As things get better, people get worse, de-solidaritized into a middle class defined by an upper class it envies and a lower class it fears. Though this common belief probably contains some truth, the historical process is far more complex. Education makes people more critical. Today more than ever before, people want full explanations before signing consent forms. Though the average quality of explanations by researchers of the risks and potential benefits of trials has probably always been better than explanations by surgeons and physicians of the risks and potential benefits of routine treatments, all have remained within the same set of cultural assumptions, in which doctors know best, and patients contribute only their bodies to the health care production process. For continued advance, we need not just formal assent, but the active use of their minds.

The high response rates obtained in the Rhondda Fach, and later in other apparently uncritically co-operative populations, tend to be seen as impossible to achieve in more sophisticated populations today. If this is true, the much larger trials we need will either not be performed at all, will have to make do with much lower response rates, will use unusual populations unable to refuse participation, or will have to start paying participants. This last solution entails large additional costs, erodes other motives for participation, may distort results by introducing new sources for potential bias, and is a one-way road from which it would be hard to return.

A wish to contribute to knowledge, and thus to help others in the future, is a powerful motive for participation in research, but this is not the only reason Cochrane achieved such high response rates in the Rhondda Fach, or the even higher rates we got in the Afan Valley. To be sustainable, population-based research of this kind requires a base in state-of-the-art routine medical and nursing care, and state-of-the-art clinical records. All epidemiological studies relate a numerator of events, strictly defined by specified criteria, to a denominator of population at risk, accurately defined and continually corrected. This means that trial participants generally get better care from better organized and more self-critical health professionals, making more use of the academic evidence base, and more open to evidence from patients and caring families. Whether randomized to a new treatment or to an old treatment or placebo, people who take part in trials consistently have better health outcomes and lower death rates than those who refuse.³⁸ Participants will participate in their

own interest, if these requirements for research are met. If they are not, the research itself must be suspect.

These material considerations do not conflict with commitment to the cause of medical science and a better future for the human race. The conflict between altruism and self-interest which liberal employers learned from their life experience was generally absent from the life experience of industrial workers. For them, the need for solidarity was a fact of life, painfully learned through generations of experience; that though some who try to rise on the backs of others succeed, most fail. Solidarity has a material basis. If participation in research seems likely to result in material gain, in either money or health or a combination of both, this benefits both participants today, and their future descendants. For class-conscious workers, solidarity and altruism are interchangeable terms.

CONCLUSION

In sum, then: the brains of patients and of research participants are in fact a huge medical resource immediately available and capable of infinite expansion, to improve care and extend knowledge. The economists' parrot cry of infinite demands pressing on finite resources is in many ways the reverse of the truth. Of course, this resource is not an already developed fact, but an agenda. To make social progress, there's nowhere else to go, though it will be no easier than any other worthwhile task.

And this is the key idea behind the south Wales Valleys project, and why this project can and should be seen as the sort of first step towards a socialist future we need to explore. Co-production of health by patients and health professionals in a commodity-free health economy has potential counterparts wherever popular culture sees a difference between production of commodities and production of value. We have already got beyond the limits of consumerism for most fields of production. We can already see the destructive effects of profit motivation for education at all levels, for all kinds of cultural production, for food production, and even for an increasing proportion of useful material objects. A very similar analysis can (and should) be applied to education, as has been applied here to health and health care.

My guess is that health care is likely to lead the field, because of the way it has traditionally been seen in our culture (more than most others)³⁹ as a field in which business may be tolerated, but will never be loved. The NHS, as originally conceived (but increasingly democratized) provides a model for what we can do now, from where we are, with the people we have, maximizing our allies, dividing and isolating our relatively few irreconcilable enemies, and basing our strategy not on the commanding heights of the economy (which are not, and perhaps never were open to us, whatever our voting majority), but on the commanding depths of our culture.

Labour Prime Minister Tony Blair is not a profound thinker, but he expresses well the assumptions underlying all current received wisdom, especially the

supposed decline of a working class imbued with a culture of solidarity, and its replacement by ‘an expanding middle class’ which will include millions of people who traditionally saw themselves as working class, but whose ambitions are far broader than their parents’ and grandparents’.⁴⁰ Blair’s conception of these ambitions is bound up with conventional notions of individual success and responsibility in a competitive market economy. Yet despite the effort put first by Margaret Thatcher, then by New Labour, into destroying the pride still felt by most people in their membership of the working class, survey research in 1997 showed that 61% of people in Britain still thought of themselves as working class, and this had hardly changed since 1979.⁴¹ Moreover, 81% actually thought there was still a class struggle in Britain in the mid-1990s.⁴² The fact that this is a massive increase over the 56% who thought there was class struggle in Britain in 1961 is perhaps not so surprising considering the class struggle from above that has been waged by the ruling classes in recent decades. Bitter experience – usually the best teacher – seems to have made people more politically literate. Yet if there is now to be a revival of class struggle from below, building on the rich tradition of solidarity in working class culture, it will have increasingly to be less about gravedigging and more about building on our knowledge so as to develop a truly democratic socialism. This is what the south Wales ‘Going for Gold’ project in health care is really about.

NOTES

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1. The creative nature of colliery labour underground, particularly before machines began to replace human labour in the 1930s, is generally underestimated. Simply to survive underground demanded imagination and understanding, so that there could be no such thing as unskilled mining labour on a large scale. The extraordinary variety and unpredictability of conditions in the south Wales coalfield made mining an essentially creative activity.
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THE DYSTOPIA OF OUR TIMES: GENETIC TECHNOLOGY AND OTHER AFFLICTIONS

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HEALTH IS THE MOST basic measure of human well-being. As such, it is the first constituent condition of any conceivable utopia. Socialists have always understood the basic truth about health which epidemiology, medical economics, sociology and biostatistics arrived at only in the last twenty years, namely that the most important determinants of health are not medical (doctors and hospitals, though these are important, especially in urban cultures) but social: economic adequacy and security, adequate shelter and nutrition, healthy living and working environments and strong families and communities. It is the combination of these factors that best predicts whether any individual will choose a healthy 'life-style', and have the means whereby to pursue it. Every individual is located in a larger social ecology of health which affects those at the top as well as the bottom. The evidence unambiguously shows that above a certain level of per capita GDP what is crucial for the health of a population is not more income per head but the degree of equality in the distribution of income and wealth.¹ Cuba's high performance on health measure in comparison with the United States is one graphic example of this. So is the fact, identified in 1998 by the World Health Organization, that due to increases in 'poverty, unemployment, homelessness, excessive drinking, and smoking' and health reforms that are too reliant on 'market forces' – i.e., neo-liberalism – Europe's overall health is deteriorating for the first time in fifty years.² From this perspective, income equalization – and all the measures needed to bring it about, including full employment, education and social supports to women (the main paid and unpaid health providers in all societies) – is the public health metapolicy par excellence.