

## RESEARCH ETHICS

## Should patients be allowed to veto their participation in clinical research?

H M Evans

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Correspondence to:  
Professor H M Evans,  
CAHHM, University of  
Durham, 14/15 Old Elvet,  
Durham DH1 3HP, UK;  
[h.m.evans@durham.ac.uk](mailto:h.m.evans@durham.ac.uk)

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Patients participating in the shared benefits of publicly funded health care enjoy the benefits of treatments tested on previous patients. Future patients similarly depend on treatments tested on present patients. Since properly designed research assumes that the treatments being studied are—so far as is known at the outset—equivalent in therapeutic value, no one is clinically disadvantaged merely by taking part in research, provided the research involves administering active treatments to all participants. This paper argues that, because no other practical or moral considerations count decisively against so doing, we could and should oblige patients to agree to receive indicated treatment within the terms of any concurrent research protocols. This ensures their treatment will benefit not only themselves but also future patients through contributing to new knowledge. By analogy with the paying of income tax, patients should not be allowed to “veto” their social responsibility to take part in clinical research.

So called “modest proposals”, those disarming challenges to our ability to say exactly what is wrong with an obnoxious conclusion, have a distinguished history,<sup>1</sup> high visibility,<sup>2</sup> contemporary relevance in this journal,<sup>3</sup> and a tendency to backfire. Defoe found himself imprisoned; see *Daniel Defoe: the Life and Strange Surprising Adventures* by R West for an account of the personal consequences to Defoe of his satirical pamphlet, *The Shortest Way with Dissenters*.<sup>4</sup> In my case the trouble so far has been embarrassment rather than anything worse, but the urge to confess is a powerful one.

Initially I put forward the following argument in the context of postgraduate teaching rather than of research as such, still less policy discussion. The argument was a device to provoke students into attacking its conclusion from the now orthodox outraged defence of patient autonomy. Unfortunately, in putting it forward, and buttressing it against the more elementary objections that were to be anticipated, I found myself reluctantly sustaining, defending, and finally succumbing to it. Here is the *initial* argument in its simplest form:

#### THE ARGUMENT IN SHORT FORM

In taking advantage of publicly funded health care, more or less free at the point of use, and consisting in more or less the best standardly available treatment for my presenting condition, I am receiving treatments that have been brought to their present state of perfection by having been tried out on other people first. In effect, I stand on the shoulders of patients who took part in past research. Do I not therefore have an obligation to bear the feet of future patients by allowing my treatment to be included in systematic research? And should I not therefore give up (or have removed from me) the veto that I currently enjoy over my own participation in relevant clinical research?

This is a sort of “fair’s fair” argument—“be done by as you did”, “don’t hand it out if you can’t take it” (or, more strictly in this case, “don’t take it if you can’t hand it out”).

The objections to the argument as I have presented it here are likely to be vehement, and to centre on (if not entirely consist in) emphatic assertions of the *moral centrality of consent to any ethically acceptable clinical research*. In the past I have lodged such objections myself, and believed them.<sup>5</sup> Now,

however, and somewhat to my own dismay, I think they can be met, as I will try to show in what follows.

#### LIMITS UPON CONSENT—AN ANALOGY WITH INCOME TAX

First let us test the water with an analogy, which aims to bring out the costs of voluntarism and (by implication) the benefits of compulsion.

Consider the payment of income tax. We all know that income tax isn’t voluntary—and furthermore we all know that it *could not* be voluntary, and that the individual taxpayer *could not* be granted a veto over his/her participation in the scheme of redistributive taxation without risking a collapse of that scheme as a whole. Collectively we cannot afford such a collapse, for it would bring with it a concomitant collapse in things for which the scheme pays—the running of our civic institutions, our public services, our national and local amenities and infrastructure, and indeed law and order.

Thus the enforced payment of income tax is among other things the enforced adoption of a pooled risk, pooled benefit, communitarian commitment to a more or less decently ordered society—something we all want to *have*, whether or not we want to pay the tax. If we left taxation to the volunteers there might well be a sizeable minority of voluntary taxpayers bailing out the rest of us through a meagre skeletal system of civic institutions and services. But it would be a poor and a fragile alternative to the enforced system we actually (albeit grudgingly) tolerate.

Well, in the same way, don’t we all want the best possible medical treatments, arrived at in the shortest possible time by the most rapid and muscular system of clinical research that is possible? Certainly, yes: I will take it as axiomatic that we do. But now consider what follows from the analogy so far: the current voluntary system no doubt enables *some* advances to be made at *some* sort of pace, but it is hardly the wholesale acceleration we might expect if the whole system were to be put on what we might call a “war footing”. A system of obligatory participation in clinical research (albeit judiciously and compassionately regulated) would provide both speed and muscle. The relatively

swift advance in the treatment of childhood rather than adult cancers owes much to the greater availability of a pool of research subjects—that is, very young children, sick or dying, whose participation in research is sanctioned predominantly by desperate parents—when compared with the available numbers of consenting adult volunteers (R Evans, personal communication, 1994).

Now of course there might be many things that we morally *ought* to do—reduce our individual consumption of the world's energy and resources, give money for overseas aid, enrol in first aid training, open our homes at Christmas time to those living on the streets, and so forth—yet which we would regard it as intolerable if society enforced our doing. Indeed, the enforcement of all moral duties would risk incoherence as a *general* principle, because it would empty our behaviour of the voluntarism that is a conceptually necessary part of most moral action. The point about the analogy with income tax is that participation in some institutions is, or ought to be, conditional: the benefits which those institutions offer come at a price. We cannot run society well without the coerciveness implicit in income tax. The analogy invites us to consider the development of new medical treatments in the same light.

But does the analogy work? In arguing that it does, I will consider seven specific objections to it showing that they are fatal neither individually nor in combination. The implications of the analogy's success will then be summarised starkly at the end of the paper. First, the objections as follows:

### OBJECTION (1): YOUR BODY IS NOT YOUR MONEY

A standard response to any attempted analogy is to deny that the analogy fits. So it might be objected here that an argument that works for income tax is one thing, but has no necessary application to something so different from our money as our very *bodies* and our bodily integrity. Your body (or your health) is not remotely the same sort of thing as your money (or any other of your worldly goods). If you like, it is one thing to pool our funds and quite another thing to pool our physiologies, the latter making no sense practically, metaphysically, or morally.

On the face of it there is some substance to this objection. We make both legal and moral distinctions between cash and corpus, and have specific constraints if not outright bans on the selling of body tissues, parts or—how shall I put this?—services.

But we need not give up the argument at this point. These constraints are placed by the state, and they can be altered or redirected or refocused by the state. They may concern primarily, even exclusively, the risks of unregulated private or commercial bodily transactions, and they may have no intended bearing on state sponsored transactions. My proposal is not at all about the sort of things that normally attract commercial transactions. It concerns putting aspects of my body's function temporarily at the service of the common good, a good in which I ordinarily share, and (as will be seen) doing so in a way that is fair, scrupulous, and relatively safe.

In that crucial respect, then, it certainly *does* resemble income tax as a way of putting private charitable—or for that matter uncharitable—transactions into the public arena where they can be conducted fairly and to the good of all: that is the whole point of redistributive taxation and the fair sharing of resources that it makes possible. Thus the analogy cannot simply be denied or dismissed.

Formal resemblance is not enough, of course. Objectors might concede the formal analogy but complain that its implications *ought not* seriously to be embraced because of

other constraints. Objections (2) to (6) inclusive embody complaints of this kind, as follows.

### OBJECTION (2): RESEARCH IS RISKY

The objection we might now turn to is that research carries the sort of uncertainties, or put more unsympathetically the risk of harms, which are unacceptable within the normal expectations of the clinical encounter. After all, when you go to see your doctor you expect that she/he will arrange advice and treatment specific to you and specifically in your interests, and you certainly *don't* expect that this will be done in the interests of generating useful knowledge. If you volunteer for research, that's your business—but not the business of the doctor or society more generally. She might sometimes invite you to contemplate the risks of entering research, but she should never expect or require it. Entering clinical research is risky in a way in which paying income tax can never be (however painful the deductions that appear in one's monthly payslip).

But this objection is naive. It completely ignores the facts of life about the clinical encounter. It ignores the uncomfortable truth that, from the moment you step into the consulting room, you have already entered the research context on at least two counts.

First, you are inevitably a beneficiary of previous research—which is being *applied* to you, courtesy of those patients who were your predecessors. Second, all clinical interventions are also experiments upon a study population of  $n=1$ , simply because your actual response to a treatment is unknowable in advance of trying it out. The minute you invite your doctor to treat you then you have volunteered for an experiment, and you must accept the risks this involves even in the ordinary clinical context.

And what, in any case, *are* the harms specifically at stake when you are enrolled into a clinical trial? It is a standard ethical requirement of research that it should involve harms, which—so far as we know at the outset of the trial—are neither more grievous nor more likely than those attaching to the usual standard treatment. This conception of “minimal harm” is a proper expectation normally attaching to any ethically appropriate experiment such as a randomised controlled trial (RCT). It may of course emerge during the trial that a particular treatment is specifically harmful to particular individuals. In properly conducted research such “adverse events” are monitored and, if serious, taken as grounds for intervening—if necessary withdrawing the individual from the trial in order to place them on better tolerated or more effective treatment.

What's more, the culpable treatment need not be the new treatment that is being tested experimentally—it may as easily be the standard treatment against which the new treatment is being compared. It may be that we discover that the current standard treatment is no good for you—and we may discover this either in the individual, “ $n=1$ ”, experiment of ordinary clinical treatment, or in the large scale controlled clinical trial. From your point of view, what counts is that we keep a close eye on you and change your treatment if it appears right to do so.

### OBJECTION (3): RESEARCH DEFIES YOUR EXPECTATIONS OF TREATMENT

Our hypothetical opponent will not give up on this point, however, going on to complain that much research is not about treatment but concerns diagnostic methods or techniques, or epidemiological data gathering that cannot possibly offer you the benefits of treatment.

Let me concede this straightaway, and deal with it by refining and limiting my proposal accordingly. First, I will

limit my proposal to only that research that happens to involve administering to you a treatment that you need in the management of a condition for which you have actively sought advice. In other words, during the course of a normal clinical encounter you are prescribed treatment, which is indicated for your condition but in which there happens also to be legitimate current research interest. The usual reason for this is the perennially provisional and uncertain nature of current medical knowledge—medicine can do so much for you now, but preferably would be able to do far more for you in the future given the necessary research. (As proof of this, look at how much less medicine was able to do for comparable patients in the past.)

We can, and should, refine the proposal still further. Let us for the time being countenance only those experimental methods in which all patients—including you—are certain to receive an active, indicated treatment, regardless of the “arm” of the experiment to which you are allocated. Now recall the expectations you have on presenting at the doctor’s surgery. You expect—don’t you?—to get the best available treatment for your condition. Well, under this proposal, *you will*.

For the expectations that drive any ethically acceptable research are, standardly, that the subjects entering the trial will receive treatment that is—for all we know—at least as good as the standard treatment. This is the meaning of “clinical equipoise”, and it is normally an intellectual as well as an ethical requirement of any research that is genuinely worthy of the name.<sup>6</sup> Let us be in no doubt about this: genuine professional uncertainty about the merits of different treatments is normally an absolute requirement for proceeding in research. Were this requirement not fulfilled it would be because clinicians already knew or strongly suspected which treatment was preferable. In such circumstances they ought obviously to prescribe the preferred treatment: clearly it would be specifically unethical to test an insubstantial or, worse, redundant question upon the bodies of patients.

Let me spell out what this implies.

Remember that when you present to your doctor, you expect to—and indeed normally will—receive the standard best available treatment. This is true of ordinary clinical treatment outside the context of a clinical trial. But it remains equally true *within* the context of genuine research predicated upon genuine uncertainty. Suppose that treatment for your clinical condition is being investigated in a clinical trial comparing the best current standard with an alternative treatment (which may be a different substance or simply different formulations or dose regimes of the same substance). You may get the current standard treatment; you may get something new or different. But in the genuine uncertainty, which is a prerequisite of ethically sound research, it doesn’t matter at the outset which treatment you get—we are logically bound to presume that there is no therapeutically relevant difference between them, and the clinical trial is being undertaken to test that very presumption.

Now it is true, as we’ve already acknowledged, that the primary objective of ordinary clinical treatment is the individual benefit of the patient, whereas the primary objective of medical (or any other) research is the generation of new knowledge and/or the reduction of future uncertainty. But these objectives are not incompatible, and whilst patients do not benefit from taking part in research *as such* neither are they disbarred from the benefits of *treatment* simply by taking part in research that involves treatment. In particular, if the ethical requirements of an RCT as noted previously are met, then your ability to benefit from treatments you will receive is totally unaffected.

I think we have now disposed of objections concerning systematic differences in the probable harms and benefits of treatments allocated in the two contexts we are considering—that is, routine clinical treatment and controlled clinical trials—when viewed at the point at which patients are enrolled in the trials. And if systematic differences emerge in the course of the trial (something the trial is far better designed to uncover than is the hurly burly of routine clinical practice, after all) then we can swiftly adjust your treatment on a properly informed basis.

There still remain, however, two further significant differences between standard clinical treatment and clinical research in the form of a RCT as described here. These are, first, that the choice of treatment in the former is made by the prescribing physician and in the latter is made by a computer-generated random number sequence; and, second, that for the period of the trial the patient and his physician may not know exactly which treatment he is receiving.

Let us deal with these matters separately, as we consider our interlocutor’s next two objections.

#### **OBJECTION (4): INDIVIDUAL CLINICAL JUDGMENT IS PARAMOUNT**

Next, then, we face the objection that it is somehow wrong or unacceptable in the ordinary clinical encounter to substitute a random treatment allocation process for individual clinical judgment, because, among other things, the clinical relationship is above all a personal and not a mechanical one.

Yet this substitution can hardly be a disadvantage if we are to take seriously the intellectual basis of the RCT, which is that the accumulation of properly controlled experimental data is respectable—because *generalisable*—in a way in which anecdotal evidence can never be. (We may leave aside the virtues of empathic interpersonal communication between doctor and patient, because they should remain intact and unaffected by the simple engagement of a research protocol with the matter of allocating treatment in a situation of genuine uncertainty.) Where the efficacy of a specific treatment is concerned the individual and personal preferences of the individual physician are of no especial weight compared with the collective evidence available to the relevant clinical community. Where genuine clinical uncertainty obtains—and, to repeat, this should be an absolute requirement for any ethically appropriate research—then the “hunch” of the prescribing physician is frankly neither here nor there. Therefore the official position of evidence-based biomedicine includes the following implication: namely that a patient whose treatment is the subject of legitimate research is not, and *logically cannot be*, disadvantaged just because his treatment is allocated randomly, and not hand-picked for him by his attending physician. In any situation of genuine uncertainty, and until (subsequent to the trial) we know more, the random sequencer is allocating therapeutically *equivalent* treatments, all of them presumed to be as good as the best current standard.

#### **OBJECTION (5): WITHHOLDING OF INFORMATION IS UNACCEPTABLE**

The remaining significant difference between the RCT and the standard clinical consultation concerns what information is known by either the patient or his own doctor. In the usual clinical context the doctor chooses the treatment, and tells the patient what she is prescribing to him, and in an outpatient setting the patient may even go and obtain it himself at the pharmacy. By contrast, in the RCT there are usually good reasons why the patient and even his doctor should not know exactly which treatment he is getting, at least until after the trial.

Well, what of it? Just what's in a name? Less, I think, than the mock affection noted by James Agate in his diary (9th April 1937) following a visit to Thorpe Bay without his antiasthma medication:

I just can't bear to run short of  
Acetylmethylidimethylamidodiphenylhydrazine.<sup>7</sup>

We can immediately dispose of one reason for needing to know the identity of the treatment, that is, to avoid predictable adverse reactions on the part of a given patient. Clinical trials have inclusion and exclusion criteria for very good reasons. These screen out people whose histories suggest special sensitivity to particular groups of drugs or other good reasons to avoid contact with them. So provided the inclusion and exclusion criteria for our RCT are genuinely fulfilled, we can assume that you as the enrolled patient are not especially at risk from any of the treatment regimes in the trial—and remember that you were going to receive *one* of these treatments in any case. Ordinarily, having excluded specific allergies or intolerances, do you really care about whether you are receiving molecule A or molecule B? Exactly what premium do you (or may you) put on being given a chemical name that you may not necessarily wish even to attempt to pronounce?

Your doctor may be profoundly interested, of course. But provided that—as any ethically appropriate trial protocol *must* provide—the “blinding” of treatment allocation can instantly be reversed in case of an adverse event, no clinical material disadvantage to you seems to follow from your doctor being temporarily and provisionally denied this knowledge. Of course, a certain autonomy is lost when knowledge is even temporarily withheld. But this is a pretty thin, theoretical sense of “autonomy”, which I doubt you would ordinarily want to exercise. The loss is substantial if and only if you would ordinarily value precisely that knowledge for its own sake. This seems, to say the least, unlikely in your own case—or in mine. And I think it is unlikely in your doctor's case, either, if the return on this “investment” of temporary ignorance is to be her/his improved ability to treat you in the future.

Furthermore, even if you do mind this provisional ignorance, I suggest that it is simply one small part of the legitimate price you are occasionally asked to pay for access to the benefits of a pooled risk, pooled benefit, collectively funded health care system. And it is indeed only an occasional matter: it is unlikely that many treatment prescriptions you receive will be provided under a trial protocol even under the “pooling” system I am contemplating. There are, among other things, simply not enough researchers, funding, or energy to bring every clinical interaction under such protocols, though the more over-worked of our research ethics committees could perhaps be forgiven for doubting me on this point.

The position we have now reached is this. As a patient, you simply are no worse off in a clinical trial: the trial costs you nothing. Notoriously you will receive, if anything, *closer* clinical attention in the trial than outside it, and because this attention is something generally sought by patients it is plausibly a net gain for you when enrolled as a trial subject. And medical research is of course the better for including you—always supposing you meet the inclusion and exclusion criteria for the trial.

Thus the costs of my proposal so far are *only* that you have had a right of veto taken away from you. What sort of a cost this is, and how weighty, we shall think about next. But it will have to be extremely weighty to overcome both the loss of the advantages listed here and the context of obligation that is at the heart of the argument with which I started—the

argument that as a patient receiving treatment you already stand on the shoulders of past research subjects, and future patients need to stand on yours.

### OBJECTION (6): MOST CANNOT OPT OUT OF “THE DEAL”

We now find ourselves facing a larger point concerning the transparency of my “modest proposal”. The proposal is, to recall, that you lose your current right of veto over participation in appropriate clinical research in exchange for your access to a system of publicly funded health care free at the point of use. When you need treatment, and moreover if—and only if—that treatment is the subject of ongoing research, then the prescribing, administering, and monitoring of that treatment will be arranged within the terms of the research protocol. And if—and only if—you want to take advantage of that treatment, then you do so with your eyes open. You know in advance that your particular treatment will be decided and appraised within a trial protocol.

Having decided to opt into such a system (or, perhaps to stay in it) then whether you are treated in a given circumstance will not depend on whether a relevant trial is going on at the time. You will always be treated, if you wish to be treated. It is simply that if a trial is indeed going on, then your treatment will be arranged within, and will contribute to, the trial. And your treatment in the trial will (to repeat) be at least as good as the current standard treatment available to you in any case, so far as the relevant clinical community can tell at the time of enrolling you; any emergent deficits will be made good as they become known.

But now you might protest that you never actually opted into such a publicly funded system at all—you never “bought into the deal”, but simply found yourself in it. (This is most obviously true of patients who were born and bred in a society that supports such a publicly funded system, rather than those who immigrated into one.) So if you didn't opt in, can you opt out—for instance, on the grounds that you disliked the terms of my pooled research proposal, if it had been implemented?

Well, of course you can, if you are prepared to pay for private health care. In buying your way out of making one kind of contribution to publicly funded health care (your physical participation in research) you at least forfeit the right to take up the benefits of others' contributions free of charge. Whether your actual monetary payments for private health care directly benefit the publicly funded system is no doubt disputable; this takes us into the detailed analysis of a mixed health care economy—something which is beyond the scope of this paper. Certainly, opting out economically may not be at all the same thing as absolving yourself from any moral responsibility to contribute to participation in medical research.

But, more immediately, suppose that you cannot afford to do anything other than opt in or stay in the publicly funded system. To be brutally honest I think this simply means that, because like all of us you stand on the shoulders of previous public health care patients, you cannot afford to do anything other than be willing to support the feet of future public health care patients. In much the same way—to return to my opening analogy—few of us can afford to buy our way out of paying income tax by retreating to a tax haven and then paying directly for the services and institutions that everyone else obtains through participation in a non-voluntary taxation system. I should perhaps make it clear that I personally do not hold private medical insurance or have any other arrangements of access to private health care. The consequences of this “modest proposal” therefore also apply to me personally.

There are, in short, some things that you can veto and some things that you cannot veto. And this is one of the things that—suggests my modest proposal—you cannot veto unless your income allows it.

Now admittedly this last consideration sounds rather dismissive, even contemptuous of the general lack of choices facing those who cannot afford to buy their way out of the constraints of publicly funded services: and that means most of us, of course. Accordingly this brings me to consider one final, serious, objection of a general kind, as follows.

### OBJECTION (7): THE LESSONS OF HISTORY, OR THE “SLIPPERY SLOPE”

Now it is precisely those people who cannot afford to make choices like these who are the most vulnerable. Modern history—since, shall we say, 1930—has shown their vulnerability to be in need of special protection, special rights, and special exemptions. And in general I would support the motives underlying these protections. But does this mean that modern history also demonstrates a special, privileged place for voluntarism and consent *in the specific context of medical research*—as, perhaps, the circumstances leading ultimately to the Declaration of Helsinki might suggest? (I owe this objection to Steven Edwards.) Does it indicate a line that simply cannot be crossed?

This is a serious objection, but notice that it is not a conceptual or logical objection to the *principle* of removing the veto. It is a historical, accidental, contingent objection. It says in effect that the special wrongs committed against some patients or pseudo patients (“patients” is hardly a tolerable name for concentration camp prisoners) in the name of medical experimentation have been so heinous, so widespread, and so disgusting that they call for special sensitivities and especially solid protections. If we override any of those protections now—as we apparently might if we adopted my proposal—then we are on a slippery slope leading to crimes against humanity.

This is a strong objection or, at least, strongly worded. Of course I agree with the political sentiments behind it—but I do not admit it as an historically plausible objection to my proposal. Since it has a historical content it can be answered historically. Or, rather, we can insist that the objection must be judged in historical terms. In particular anyone relying on it must show that the circumstances of, say, a pooled research national health service are in relevant ways so sufficiently similar to those that produced past atrocities as to make those very atrocities the author of our present rules.

But it seems clear that the circumstances are not remotely similar. No one who was a victim of them “bought in” to the general circumstances of the Nazi death camps. There was no “deal” involving reciprocal advantages, which would be waived if the costs were waived. The circumstances of what passed for medical care in the camps themselves bear no resemblance to the modern day National Health Service (NHS) as it operates in the UK today. The motives and methods (and indeed in many instances the scientific conceptions) of those undertaking the Nazi experiments were in the main diametrically opposite to the motives and methods in contemporary medical research. To doubt this is to impugn the entire basis on which we as patients *voluntarily* avail ourselves of current treatments, as well as to vilify those who develop and provide them—the very people whom we voluntarily consult as our doctors. Indeed it could be said that basing our regulation of the actions of contemporary medical researchers even in part on our repudiation of the Nazi butchers is to begin to impugn and to vilify, if only implicitly, our own medical research community. In a rather similar way, to tailor the governance of general practitioners towards the attempted prevention of another Harold Shipman is,

implicitly, to put all general practitioners within walking distance of the dock in which Shipman stood arraigned. Public overreaction to a genuine scandal can itself be scandalous in its consequences.<sup>8</sup>

### CONCLUSION

I think I have shown that all these objections fail. If there are others that are more effective, I will be glad to learn of them—not least because I myself find the “modest proposal” as disconcerting as it is seemingly irresistible. If there are no effective objections, then I think my modest proposal must succeed—and that when you next consult your doctor you should join me in calling for the removal of the patient’s veto over entry into clinical research, and (of course) should waive the veto yourself at the first opportunity.

When I put it in those terms, even if you agree with my arguments, you may none the less recoil again from what it *sounds as if* I might be proposing. So let me finish by emphasising once again just how limited a proposal it really is. I am proposing nothing more than the following:

*If (1) you go to your doctor in search of treatment, and if (2) you are prescribed a type of treatment, which your doctor competently judges that you need or from which you could benefit, and if (3) that type of treatment happens to be the subject of ongoing clinical research in a context of genuine equipoise (clinical uncertainty about which is the best available treatment), and if (4) you meet the inclusion and exclusion criteria for entry into the relevant trial, and if (5) that trial is so designed that everyone enrolled in it will receive some active treatment or other whose relative merits are genuinely unknown and thus sincerely assumed to be equivalent when you enter the trial THEN I think it is your duty as a beneficiary of the pooled cost, pooled benefit NHS system to do for future patients exactly what past patients have done for you—that is, you must receive the treatment within the parameters of the clinical trial in question.*

It is, in sum, your duty to take part as a subject in research, which can lead to the improvement of future treatments. In properly scrutinised and properly monitored research, there is no basis for fearing that any harm will come to you *from the taking part*. Much good may, and hopefully will, come to others.

And because not everyone can be relied on to do their duty, in clinical research any more than in contributing to nationally shared welfare, then responsibility for the decision must be given to others. You should be entered into the research automatically, and if you want to obtain treatment in these circumstances then you should no more have a veto over taking part in the research than you should have a veto over paying your income tax.

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