

BOARD OF GOVERNORS

**Review of Consequences of Additional Private Drugs for NHS Care:
Results of Consultation with Patients and Clinicians**

BACKGROUND

In July 2008, the Secretary of State for Health announced that he had asked Professor Mike Richards, National Clinical Director for Cancer, to review policy relating to patients who choose to pay privately for drugs not funded on the NHS and who, as a result, are required to pay for the NHS care that they would otherwise have received free. This review of top-up payments, or co-payments as they are sometimes known, will make recommendations on whether the current system should be changed, and if so how. It will report in October and its findings will be made public.

In order to gather views and evidence from all sides of the debate, the review team at the Department of Health devised two questionnaires, one for patients and the other for clinicians, and encouraged Trusts to use them to canvass the views of their own patients and clinicians.

Cambridge University Hospitals NHS Foundation Trust (CUH) welcomed the national review, and the opportunity it afforded to ascertain the views of its patients and clinicians on this increasingly prominent issue. The Trust therefore adapted the national questionnaires slightly and administered them, either electronically or in printed form, in the period 1–20 August. The electronic questionnaires were created using Bristol Online Surveys software. Data from completed printed forms were entered electronically by members of the CUH Clinical Audit Department.

Electronic questionnaires were sent to about 3000 patient and public members of CUH Foundation Trust, and printed questionnaires were provided to about 500 patients by reception staff in the Oncology Outpatient Department, Clinic 4 (Surgery), Clinic 5 (Gastroenterology) and Clinic 7 (Dermatology). The Medical Director sent electronic questionnaires to 450 consultants in the Trust, and other clinical staff were alerted to the questionnaire through networks.

RESULTS

Patients

802 CUH patients completed questionnaires (response rate ~23%). Patients were invited to add their own comments on several of the questions, and many did so. Appendix A1 shows how patients voted, and Appendix A2 gives representative examples of patients' responses to the question that attracted most comments, namely Question 10 (Please use this space to tell us any other comments you have on this issue).

As Appendix A1 shows, patients voted very strongly in favour of allowing co-payments. For example, in answer to Question 1 (Do you think in principle that people should be allowed to supplement their NHS care by opting to pay for additional drugs not funded by the NHS?), 659 (82%) voted yes and 89 (11.1%) voted no, with 54 (6.7%) voting don't know.

Clinicians

56 CUH clinicians (42 consultants, 10 nurses, 2 clinical scientists, 1 allied health professional and 1 clinical research manager) completed questionnaires (consultant

response rate ~9%). Clinicians were invited to add their own comments on several of the questions, and most did so. Appendix B1 shows how clinicians voted, and Appendix B2 gives representative examples of clinicians' responses to the question that attracted most comments, namely Question 12 (Please use this space to tell us any other comments you have on this issue).

As Appendix B1 shows, clinicians voted very strongly in favour of a relaxation of the current policy for 'proven' drugs. For example, in answer to Question 1 (What is your view on supplementary payments for 'proven' cancer drugs which are unavailable on the NHS?), 51 (91.1%) voted to allow them, 3 (5.4%) were opposed, and 2 (3.6%) voted don't know. The responses of the 10 nurses in the survey were not systematically different from those of the doctors: for example, in answer to Question 1, 9 nurses voted to allow 'proven' cancer drugs and 1 voted to oppose them. Clinicians were much more cautious about 'unproven' cancer or other drugs, about 35% opposing their use.

A complete dataset of patients' and clinicians' responses is available as an analysable Excel spreadsheet or as a set of Word documents from:

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The Trust is grateful to Jane Robinson, Fraser Rogers and members of the Clinical Audit Team, who administered the questionnaire, to reception staff in the Oncology Outpatient Department, Clinic 4 (Surgery), Clinic 5 (Gastroenterology) and Clinic 7 (Dermatology) and to all patients and clinicians who responded.

Mary Archer
28 August 2008

**Review of Consequences of Additional Private Drugs for NHS Care:
CUH Patient Questionnaire Results**




Survey Overview

Number of respondents: 802

Launch date: 01 Aug 2008

Close date: 20 Aug 2008




1. Do you think in principle that people should be allowed to supplement their NHS care by opting to pay for additional drugs not funded by the NHS?

Yes:		82.2%	659
No:		11.1%	89
Not sure:		6.7%	54

2. Would it be acceptable to allow those patients who can afford it, to supplement their NHS care with private drugs (if some other patients do not have the money to do this)?

Yes:		79.1%	634
No:		12.2%	98
Not sure:		8.7%	70


3. If people are allowed to supplement their NHS care, would it be acceptable for the NHS to pick up any costs associated with giving the drug (for example, blood tests, nursing time, management of any side effects etc)?

Yes:		61.0%	489
No:		24.3%	195
Not sure:		14.7%	118

4. Do you think that patients should be allowed to supplement their NHS care with private drugs which their doctors have said "could" be of benefit, but are not available on the NHS?

Yes:		86.3%	692
No:		6.7%	54
Not sure:		7.0%	56

5. Turning now to your personal experiences, have you ever needed a drug for your condition that the NHS would not pay for?




Yes:		3.9%	31
No:		96.1%	771

6. If yes, which drugs and when did this happen (please list)?





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- There are too many responses to display on this page and so all the responses to this question are available on a separate page.

7. If you had had the opportunity to supplement your NHS care by paying for these drugs, would you have wanted to do so?

Yes:		54.7%	122
No:		26.0%	58
Not sure:		19.3%	43

8. If not, why not? (You may tick more than one answer)





I would not have been able to afford it:		n/a	55
I disagree in principle:		n/a	34
It would not have been worth the expense:		n/a	1
Other:		n/a	10

8.a. If "other", please specify

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9. If yes, up to how much in total would you have been willing to pay?

Under £10,000:		55.7%	64
Up to £20,000:		13.9%	16
Up to £30,000:		0.9%	1
Over £30,000:		29.6%	34

10. Please use this space to tell us any other comments you have about this issue

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- There are too many responses to display on this page and so all the responses to this question are available on a separate page.

Representative patients' responses to Q10 (Please use this space to tell us any other comments you have about this issue).

IN FAVOUR OF CO-PAYMENTS

A patient's choice to pay for drugs should not diminish his entitlement to the NHS care he would have had if he had not so chosen.

You would be outraged if the doctor said that he could not treat you because you were buying your own paracetamol. So where do you draw the line for privately purchased medicines?

Financial limits will ALWAYS mean that some drugs that would have therapeutic benefit cannot be made universally available — why else does NICE exist? This is the fundamental reason why people should be allowed to top-up their treatment while still largely retaining NHS care.

Given that these broad arguments also apply to private schooling, BUPA et al, housing and many other categories where issues affecting health can be purchased, it seems absurd not to include direct medication options ...

I believe that in the case of a patient opting to pay for additional treatment the NHS should continue to provide for free the treatment it would normally provide so long as the additional treatment has been approved by the NHS as not interfering with or having adverse effects on the standard NHS treatment regime.

I can't see that this differs in principle from topping up state education with private lessons, to name but one example.

I consider it iniquitous to suggest denying people access to a service for which, lifelong and by law, they have paid by way of Income Tax and Nat. Insurance. I earn my income by the sweat of my brow. I pay and have always paid my taxes on the nail. If I choose not to drink, not to smoke, not to take drugs, not to abuse my body by a variety of excesses, and therefore to have the option of additional remedies, what right has the Government to penalise me for my thrift? What right has the NHS to deny me treatment simply because I might have chosen to purchase, with my own hard-earned and carefully administered money, a preparation which I believe to be beneficial to my health and which is not available to me on the NHS? Would the same apply to my paying for a dental crown rather than having the tooth removed? Would the same apply to the practice of keeping Elastoplast in the house against an accident? Provided that I act responsibly (unlike so many people who wilfully wreck their own bodies with tobacco, drunken driving, excess food, irresponsible lifestyles and then turn to the NHS to be patched up), I believe that to deny me NHS treatment would be radically unjust and would amount to outright theft. It's an utterly crazy notion. Incidentally, how could it possibly be monitored? And all this from a Government that bleats about choice!

I find it ridiculous that some people say that paying for extra drugs makes a two tier system — there is already a two-tier system. Those who can afford private care do so. Those who can't stay with the NHS. Why should there not be a third way? Paying for your own drugs benefits the NHS surely?

I would also extend this to paying for extra care such as physiotherapy. A friend with young children recently had a stroke and requires extensive physiotherapy. They would dearly like to pay for extra hours but fear losing all NHS help if they do so.

If there is medication available of proven, or even probable, benefit that the NHS, for reasons of economy, will not provide, then of course those who can afford it will pay for

such medication themselves. The suggestion that, should they do so, other NHS treatment, support, and medication will be withdrawn from them is quite simply monstrous. It is to punish people for acting upon one of the most basic instincts - the instinct for personal preservation. It would almost certainly be successfully challenged under equity and under Human Rights legislation. The suggestion that those paying for supplementary treatment are being unfair to those who cannot pay is absurd. If there is unfairness here, the unfairness lies in the refusal of the NHS to pay for such treatment. That said, the NHS cannot be expected to pay for every possible treatment for every possible condition in every possible case. But the financial limits of treatment must be transparently established; and if the NHS cannot afford to treat patients, there can be no possible moral justification for its then refusing other, normally available, treatment for such people on the grounds that they have helped themselves where the NHS could not do so. If such is indeed the current policy, it is despicable and must be amended at once.

...The NHS must not continue to solve its problem by "upholding a principle" with the consequence that possible health improvement is denied and that survival rates for cancers and other serious illnesses are lower in Britain than other West European nations by refusing a top-up system without withdrawing NHS support ...

The NHS should be pleased I am willing to supplement drug costs to aid my treatment rather than using it as deterrent to my being able to continue with NHS treatment. In my opinion as the situation stands it infringes on my human rights.

AGAINST CO-PAYMENTS

Disagree with whole concept; I would gladly increase my taxes to ensure free NHS treatment for all.

I pay lots for my NHS care so expect to receive all medical required from the NHS.

In principle all effective drugs should be available to everyone without having to pay extra to what we all pay as so called National Insurance Contributions. Although I believe people should be allowed to pay for drugs not funded by the NHS I fear that this practice could be the thin end of the wedge in requiring everyone to pay for some or all drugs.

DON'T KNOW

This is a moral minefield! Ideally the NHS should fund any drug that is of potential benefit to a patient. I am sceptical about the sort of cost-benefit analysis provided by NICE; it can only cope with the "average" patient — who does not exist. And then there is the problem of treatments for rare conditions, where a statistical basis for calculating cost-benefit may not exist. However, I think that the clinician should be able to make strong and reasoned justifications why he or she believes that the proposed therapy will benefit the patient, and that reasoning should be subject to a peer review from outside the clinical team.

This is a very difficult issue for all of us. We all want the best possible treatment available but obviously drugs are an expensive item. If patients have the money and the resources to pay and continue to pay then that's fine but those patients who haven't the resources in it would be great to know that the expensive drugs are available. What a horrible dilemma.




**Review of Consequences of Additional Private Drugs for NHS Care:
CUH Clinician Questionnaire Results**




Survey Overview




Number of respondents: 56




Launch date: 01 Aug 2008

Close date: 20 Aug 2008

1. What is your view on supplementary payments for "proven" cancer drugs which are unavailable on the NHS?			
I oppose them:		5.4%	3
I think that they should be allowed now:		91.1%	51
I don't know:		3.6%	2




2. What is your view on supplementary payments for other "proven" drugs which are unavailable on the NHS?			
I oppose them:		5.4%	3
I think that they should be allowed now:		89.3%	50
I don't know:		5.4%	3

3. What is your view on supplementary payments for "unproven" cancer drugs which are unavailable on the NHS?			
I oppose them:		35.7%	20
I think that they should be allowed now:		44.6%	25
I don't know:		19.6%	11




4. What is your view on supplementary payments for other "unproven" drugs which are unavailable on the NHS?			
I oppose them:		33.9%	19
I think that they should be allowed now:		46.4%	26
I don't know:		19.6%	11

APPENDIX B1

5. Do you routinely discuss the issue of drugs that aren't funded by the NHS with your patients?

Yes:		39.3%	22
No:		17.9%	10
Does not arise in my practice:		42.9%	24

6. Are you allowed to apply under exceptional circumstances to your PCT for unfunded drugs?

Yes:		58.9%	33
No:		5.4%	3
I don't know:		35.7%	20

7. In the last 6 months, for how many patients have you applied for funding under exceptional circumstances to your PCT?

[View All Responses](#)

- There are too many responses to display on this page and so all the responses to this question are available on a separate page.

8. In the last 6 months, how many patients in your practice have received unfunded drugs through PCT funding on an exceptional basis?

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8.a. In the last 6 months how many patients in your practice have received unfunded drugs through private funding?

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- There are too many responses to display on this page and so all the responses to this question are available on a separate page.




9. If patients were to be allowed to make supplementary payments for drugs which are not funded on the NHS, should these be delivered:

In standard NHS facilities:		87.5%	49
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APPENDIX B1

In a separate area (e.g. a private wing of an NHS hospital):		10.7%	6
I don't know:		1.8%	1

10. Are you a:





Consultant (Doctor):		75.0%	42
SpR:		0.0%	0
SHO:		0.0%	0
Nurse:		17.9%	10
Radiographer:		0.0%	0
Pharmacist:		0.0%	0
Other:		7.1%	4

10.a. If "other", please specify

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- There are too many responses to display on this page and so all the responses to this question are available on a separate page.

11. What is your speciality?

Oncology:		10.7%	6
Medicine:		37.5%	21
Surgery:		10.7%	6
Other*:		41.1%	23

*Clinicians from the following "other" specialities replied to the questionnaire: Acute pain 1, Anaesthesia 1, Audiology 1, Clinical Pharmacology 1, Critical care 2, Emergency medicine 1, General medicine / Dept Medicine for the Elderly 2, Gynaecology / Oncology 1.

12. Please use this space to tell us any other comments you have about this issue

[View All Responses](#)

- There are too many responses to display on this page and so all the responses to this question are available on a separate page.

Representative clinicians' responses to Q12 (Please use this space to tell us any other comments you have about this issue).

IN FAVOUR OF CO-PAYMENTS

Denying patients access to standard NHS care, on the basis of treatment options they have chosen, must be a denial of human rights and surely illegal.

I think it is absolutely disgraceful that patients who pay for drugs privately because the NHS won't supply them are then not given access to NHS care to which they have contributed for their entire working lives — the system is quite ridiculous. You are allowed to drink your way to oblivion and then be treated by the NHS, but not to save for treatment the NHS won't provide and then be expected to pay for NHS treatment as well.

The current situation is absurd. It is permitted to buy almost any additional therapy outside the NHS to supplement your therapy particularly things that don't work (reflexology, homeopathy) but you can't buy things that do work on wholly misguided ideological grounds — if everyone can't have it no-one should have it. Whilst I can't afford an Aston Martin I'm not against allowing those who can to use the public roads.

AGAINST CO-PAYMENTS

One cannot have differential treatment in the same area the NHS has to be seen to be fair and equal. It is the QALY adjustment that needs to be questioned. As on the TV how do you quantify 2 years of a young man's life when he wishes to see his daughter going to school against other treatments e.g. plastic surgery etc which is not life extending but enhancing.

DON'T KNOW

Extremely difficult issue. NICE decisions probably need to be speeded up and we need to consider having increased funding for exceptional circumstances to allow us to provide newer proven but not yet/non nice approved drugs where it is clearly justified. The number of patients involved in oncology is not large. The DH is correct in looking at excessively high pricing of new oncology drugs by the Pharmaceutical industry.

I am aware that this is a contentious issue and although I am committed in principle to an NHS free at the point of delivery, if I or a member of my family required drugs unavailable on the NHS I personally would go to great lengths to obtain them. This particularly applies to proven drugs for life-threatening illnesses.