Free at the point of delivery – reality or political mirage?

Case studies of top-up payments in UK healthcare

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Doctors for Reform

Doctors for Reform is an independent, non-party group which believes that the time has come to look at new ways to supply and fund healthcare. We aim to start and participate in a proper and informed national debate on the choices ahead of us. The issues are beyond party politics and we believe that, as professionals, we will make a profound mistake if we leave this debate to politicians.

Doctors for Reform is supported by the independent, non-party think tank Reform (www.reform.co.uk). However, we wish to maintain our identity and integrity as an independent doctors' group, and we do not necessarily endorse all of the views of Reform.

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Executive summary

- It is commonly said that healthcare in the UK is "free at the point of delivery". In fact this mantra is now a political mirage rather than a day-to-day reality.
- Here we examine a series of twenty case studies which show that patients are beginning to develop sophisticated approaches to purchase upgrades to their basic NHS care. These case studies, drawn from everyday NHS practice, reflect our experience as clinicians within the service. The case studies range from the major killers (cancer and heart disease) to areas of medicine benefiting smaller groups of patients (e.g. maternity services and audiology).
- We identify three key reasons for the use of top-up payments:
  - The varying limits of the NHS care package in different localities; and
  - The limits on NHS quality, including waiting times, delays and service access; and
  - The reduction in costs of some private treatments due to advances in technology and the development of a competitive marketplace.
- We also draw attention to factors which are hindering patients' ability to build on their NHS entitlement:
  - The lack of transparency concerning patients' options and PCT decision-making;
  - The view – wrongly-held – amongst some doctors and managers that it is not possible to "top-up" the NHS package; and
  - The difficulty the NHS system has in coping with requests that are reasonable but disruptive to the existing bureaucracy.
- Some may argue that the use of such top-up payments will diminish as public funding for health increases. We would disagree, pointing to several trends, now well-established in the health debate: the upwards pressure on medical costs; the limits to tax-financing; and, most importantly, the increasing importance of consumer choice.
- A key factor here is the supply-side reforms that are currently under development in the NHS in England. The progress of the reforms has been uncertain but it remains a possibility that a new NHS "market" could emerge giving some new choices to patients, including voluntary and for-profit providers. If this does happen, a greater variety of supply will hugely increase the likelihood of new kinds of demand.
- It is also crucial to understand that top-up payments are entirely legal within current NHS legislation.

- The UK healthcare system is therefore closer to Continental systems of mixed funding than many would think. But we are far behind in terms of the coherence of our funding system and in terms of equity. We run the risk of achieving the worst of all worlds: inequitable NHS provision combined with inequitable provision outside of the service. In both worlds the least well-off are disadvantaged.
- What is urgently needed is a proper debate on the future of healthcare funding, covering both tax and independent financing, based on the fundamental NHS principle that care should be universally and equitably available. By perpetuating the political mirage of a service completely free at the point of delivery debate is conveniently stifled.
- Health professionals need to be at the heart of this debate. We will make a profound mistake if we leave this debate to politicians.

1. Introduction

Costs are spiralling out of control in every healthcare environment. Ageing populations with a wide range of medical problems are consuming increasing amounts of care costs. New technology – drugs, devices and procedures – are powerful inflationary drivers in an information rich, consumer-oriented world. Direct-to-patient marketing using advertisements and more subtle public relations activities to generate positive press stories are increasingly-used tools of the pharmaceutical and medical device industry.

Different healthcare systems are using a variety of approaches to dampen demand. Rationing, both overt and covert, inevitably leads to inequity. Britain's NHS is undergoing a slow reform process. But huge variations exist in the way patients access its services depending on their location, education and socio-economic background. There are also major differences in prioritising services by those responsible for their payment – the Primary Care Trusts.

NHS spending is now at unprecedented levels. Over £90 billion is being spent this year alone. Yet the quality of service provision and access to technology does not generally match that of our European neighbours. The sense that a transformation in funding has not delivered a transformation in outputs is leading towards a new interest in methods of healthcare financing, whether a different form of tax-financing based more directly on patient choice, an insurance-based system, the greater use of co-payments or – as in some Continental European systems – a mixture of all of these.

Here we examine the growing use of "top-up" payments to break through the access barriers in the NHS. Politicians of all persuasions are in denial about their existence and are reluctant to get involved in debate on the issue. Yet as we show here, patients are beginning to develop sophisticated approaches to purchase upgrades to their basic NHS care.

The following sections seek to illuminate three central developments which are leading to the development of new services around and on top of the NHS core package:

- The varying limits of the NHS care package in different localities.
- The limits on NHS quality, including waiting times, delays and service access.
- The reduction in costs of some private treatments due to advances in technology and the development of a competitive marketplace.

We then present case studies[1] which demonstrate barriers to the development of new services:

- The lack of transparency concerning patients' options and PCT decision-making.
- The inability to "top-up" the NHS package without having to effectively pay twice.
- The difficulty the NHS system has in coping with requests that are reasonable but disruptive to the existing bureaucracy.

Lastly we present scenarios of future service delivery where patients can top-up, demonstrating benefits including cost savings.

[1] The case studies used in this report are based on real patients whose identity has been disguised.

2. Limits on the NHS care package

1. Primary care

- A 34 year old lady has debilitating axillary hyperhidrosis (over-active sweat glands). She cannot wear some articles of clothing and shuns giving presentations which is hampering her career in marketing. She has tried topical treatments with only limited success. Surgery is been suggested but this carries significant risk. Axillary botulinum toxin injections are easy to perform with minimal side effects. Unfortunately her local NHS does not provide these. She finds a local private clinic where a suitably trained GP performs the procedure for £400. This is highly successful giving a long term problem free existence. Her life and career is transformed.

2. Primary care

- A 42 year old lady attends her GP with multiple seborrhoeic keratoses. These are unsightly and some are catching on her clothing causing her inconvenience. These are deemed to be cosmetic and therefore no treatment is available on the NHS. She attends a private clinic where she is successfully treated with cyrotherapy. The total cost of treatment is less than £200.

3. Primary care

- A 49 year old man has a problem which is creating leg pains. He is a keen runner and keeps fit. This pain is preventing him from exercising which is of health benefit. He is assessed by his GP who thinks the problem could be solved with orthotics. However he can only obtain these on the NHS by referral to an orthopaedic surgeon and a significant wait. Podiatry is not available locally on the NHS. He pays privately to have a podiatry assessment. This results in some orthotics and exercises which solve his problem.

4. Infertility services

- A 33 year old secretary has been trying for a baby for 4 years with her partner. She has recently found out that she is very unlikely to get pregnant naturally and fulfils the criteria for a free IVF cycle funded by the NHS, according to NICE guidance. Her GP wants to refer her for IVF at the local fertility centre, however her local PCT is in debt and has exercised its choice not to fund a cycle in this financial year. She is desperate not to wait any longer as her chances of getting pregnant – even from IVF – will be diminishing year-on-year and she would dearly love to have two children. She doesn't want to wait any longer and her health insurance doesn't cover fertility treatment so she sets about raising the money – about £3,500 – to cover one cycle of the complete treatment and drugs at a London IVF clinic.

3. Limits on NHS quality, including waiting times

5. Physiotherapy

- An 83 year old widow who lives alone gives a one year history of increasing back pain. She is referred by her GP to the back clinic in the local general hospital. After waiting four months she is seen by a physiotherapist who examines her and suggests an MRI. After this has been obtained and the result is available she will see the orthopaedic consultant. The waiting time for the MRI is six months. One of her daughters arranges the scan the following week by paying for it privately at a local independent hospital at a cost of £480 using her credit card. The same hospital has the contract with the NHS in the area and ironically if she would have waited her scan would have been done on exactly the same machine but at a much later date. The MRI shows nerve entrapment and she is seen by the consultant promptly on the NHS and given effective physiotherapy. She obtains considerable pain relief and is able to return to her normal activity level immediately.

6. Mental health

- A 37 year old woman presents to her GP with features of anxiety and depression manifesting itself as lack of control in her eating patterns with evening binges of high calorie foods. She is referred to the local psychiatric hospital who have very tight referral guidelines and refuse to accept her suggesting that she should be managed in primary care by the practice counsellor. Unfortunately the counsellor already has a three month waiting list and is refusing to take on new patients. The community mental health team is consulted who suggest referral to the local psychiatric hospital. After a delay of over a month she elects to seek a private consultation and is found to have severe depression with bulimia. She decides to fund her own care involving psychotherapy and medication.

7. Chest medicine

- A 50 year old man has a degenerative neuromuscular condition. He suffers from frequent chest infections that are debilitating. A limited number of cough assist devices costing £2,000 are available for loan from a charity. However all devices are currently in use long term and the patient on the advice of his chest physician purchases his own. The frequency of infection is drastically reduced.

8. Cancer

- A 46 year old woman with early breast cancer is recommended aggressive chemotherapy after surgery to reduce the risks of recurrence later. She finds out on talking to other patients in her support group that the side effects are

horrendous. She wishes to obtain a second opinion from a specialist breast cancer unit involved in state of the art clinical research. Her GP requests this from her local referral management team but it is turned down. The patient pays £250 to obtain the consultation privately.

9. Hearing aids

- A 76 year old widow is developing increased deafness. The removal of a benign tumour on the hearing and balance nerve left her completely deaf in the right ear and her hearing has diminished on the left side. The lack of hearing on one side severely limited her ability to localise sound and was also troublesome communicating in group settings. Her ENT consultant advises her that he can implant a new bone-anchored hearing device to improve her hearing. Unfortunately budgetary restrictions by his NHS Trust limit the number of devices he can implant to five per year. His waiting list is already five years long. By making a payment of £2,500 she purchases the device from the private sector which is then installed privately. Her hearing and therefore social interaction improved dramatically. In other parts of the country there are no budgetary restrictions to the number of such implantations on the NHS.

10. Maternity services

- A 34 year old teacher is in her first pregnancy and booked at her local unit in a busy district general hospital which delivers 3,000 babies per year. This is a large unit by European standards, but there have been some highly publicised clinical problems and the hospital has also had difficulties with medical and midwifery staffing. All is going well in her pregnancy so far, but she is concerned that her local maternity unit is unable to guarantee one to one midwifery care in labour. After making enquiries, she decides to transfer her care to a neighbouring NHS unit where a fee of £2,500 guarantees a named midwife to meet her before her due date, look after her in labour and help her afterwards. She regards the fee as steep but a price she is willing to pay for peace of mind. Furthermore, the hospital re-invests the money in the NHS maternity unit which she sees as an equitable way of improving the services for others too.

11. Audiology

- An elderly gentleman breaks his hearing aid and needs a new one to continue normal life. In his part of the country he faces a wait of over a year. His quality of life is so badly damaged that he decides to dip into his retirement savings to spend thousands of pounds on an aid from a private provider.

12. Stroke rehabilitation

- An elderly patient had a slight stroke and was investigated. Investigations showed that an artery in the neck was severely narrowed. Surgery was advised to clear the narrowing, but he discovered that in other countries such narrowings are now treated by keyhole surgery, placing a metal strut or stent over the narrowing and removing the need for surgery. This prevents damage to nerves around the artery, and avoids a high risk of a heart attack during surgery, which affects one in five. He discovered that only 30 such procedures were done in the UK, and that this appeared to be due to surgery being favoured. He discovered that over 4,000 cases were done with a stent in France each year, where private providers get more encouragement to take up new technology and techniques, and patients get to choose for themselves what treatment they get, covered by insurance. He went abroad for his procedure. This took 30 minutes and was done through a needle in the leg. The procedure cost him £4,000, but he felt very happy to avoid surgery.

4. New technology is improving access and choice

13. Cancer

- A 29 year old lawyer with a young baby presents with pancreatic cancer that has spread to her liver, lungs and abdominal lymph nodes. She is offered standard chemotherapy which is delivered in the normal way. She has studied the literature available on the internet and has come across a new but expensive drug – Tarceva – licensed by the US authorities for use in exactly this situation. It is taken as a tablet once daily. It is available in the UK but not approved by NICE for this indication. After full discussion with her consultant she investigates the cheapest way to obtain this drug which costs around £100 per tablet if purchased in Britain on a private prescription. After shopping around, she obtains it from Canada through a reliable internet pharmacy for £35 per tablet and 3 months supply is delivered to her home by courier two days later. Gratifyingly she responds to her medication and her disease stabilised.

5. Lack of transparency in NHS entitlement and decision-making

The issue of having a combination of NHS supplied drugs and opting to pay for extra chemotherapy drugs is a thorny one. Many NHS cancer units will not allow a patient to receive privately purchased drugs whilst in an NHS unit, the only option then being to purchase the whole package of chemotherapy care privately at crippling expense. We believe that this is deeply unfair and a fundamental denial of the patient's right to NHS treatment which should not be predicated on the basis of not purchasing extra drugs that might improve their outcome. Furthermore the secrecy surrounding case by case decision making by PCTs is an alarming recent development. Clearly this aims to prevent the opening of the floodgates to new therapies. Second opinions are often sought by desperate patients and their carers. Requests are now undergoing increased scrutiny through referral management groups and are frequently refused.

14. Cancer

- A 47 year old father of three had a colectomy for colon cancer three years ago. He now presents with upper right abdominal pain and is found to have multiple liver metastases on a CT scan. He is offered chemotherapy at his NHS hospital using three drugs – 5 fluorouracil, folinic acid and oxaliplatin. He has heard about a drug called Avastin which when added to the above regimen improves both the percentage of patients responding and their survival. Although licensed for metastatic colon cancer in the UK, it is not available for financial reasons on the NHS although it is standard treatment in France, Germany and Italy as well as the US. It is also covered for this indication by all major UK private medical insurers. The drug is not mentioned by his consultant until he asks about it. He is told that he will have to get all his treatment at the local private hospital if he wishes to receive Avastin and the total bill may exceed £20,000 for six months care. He is not informed that he could receive the Avastin privately and the other drugs from the NHS. He elects not to pursue Avastin.

15. Cancer

- A 73 year old retired chest physician who has never smoked develops non small cell lung cancer. He is a well known figure in the local area. Two cycles of conventional chemotherapy produce little response. A molecularly targeted drug for this disease has just been licensed for use across the EU but has not yet been assessed by NICE. His PCT initially turn down his treatment consultant's request to fund it. The patient's condition deteriorates and the PCT is consulted again. They agree to fund three months supply but insist their decision and the reasons for it remain confidential.

6. Inability to "top-up" the NHS package, forcing patients to effectively pay twice

16. Primary care

- An anxious 59 year old man has taken a branded anti-hypertensive (blood pressure lowering) drug for many years which is in capsule form. This controls his blood pressure. In accordance with guidelines encouraging the use of generics his GP changes his medication to a cheaper generic form which is a tablet rather than capsule. A letter is produced and sent to all patients explaining the reason for the change together with the next repeat prescription. The patient obtains the prescription for the new generic tablet paying the charge of £6.85. Unknown to his GP the patient finds it psychologically difficult to swallow some types of tablets. The patient is reticent about taking the new tablet and feels "slightly dizzy" when he takes it. After a few days he stops taking it. It is not until the next consultation that his now raised blood pressure and the reason for him not taking the tablet are discussed. Despite there being no pharmacological difference between the two forms of medication the GP sensibly changes the patient back to the original form of the drug after some discussion. The patient understands that it is his preference to have the more expensive capsule and offers to pay the difference. The GP explains that this is not possible unless the patient agrees to pay entirely privately for this drug.

17. Maternity services

- A woman aged 38 is in her third pregnancy. She has a 10 year old and a 6 year old by a previous marriage. She is on income support. Though she does not want to have a baby with Down's syndrome, the local hospital offers only a "double" blood test which will identify about 60 per cent of babies with Down's. She doesn't want to have an amniocentesis – the only way of knowing "for sure" – as it has a 1 per cent risk of causing a miscarriage. She cannot afford a private combined nuchal with biochemistry test with a 90 per cent likelihood of picking up a pregnancy affected by Down's, which is offered for £160 at the local private hospital. In the end, she has the double test which gives her a "low risk" result, so she is reassured. Had she chosen the private combined nuchal with biochemistry test she would have had to pay the full cost of this and then would not have received the "double" test to which she was entitled.

18. Cardiology services[2]

- Current NICE guidance limits the use of drug eluting stents (DES) to the treatment of patients who have coronary artery stenoses that are greater than 15 mm in length or in vessels less than 3 mm in diameter. Other patients should receive a bare metal stent (BMS). However, the trial evidence shows clinical benefit for the use of DES in patients with lesions of all lengths and sizes.

  "Desmond, a 45-year-old man with typical stable angina and a positive exercise test, was referred for coronary angiography. This revealed a short (12 mm), but tight (90 per cent stenosis) discrete lesion of his 3 mm diameter proximal left anterior descending artery. In view of his symptoms Desmond agreed percutaneous angioplasty was an appropriate treatment. He was referred to the local NHS service for this treatment. During the process of consent Desmond was concerned that any stent used would remain where it was deployed for his lifetime. He asked specifically about the best type of stent and then whether he would receive a DES. The clinical evidence was explained and Desmond was told that NICE guidance meant he would receive a BMS. He was able and willing to pay for the difference in cost between a BMS and the DES but did not feel he could justify the full costs of a private procedure with a DES. The issue became whether Desmond could pay a top-up fee and receive a DES in the context of the NHS procedure. For most practical purposes the only difference between the insertion of a DES and the insertion of a BMS is which stent is taken off the shelf during the procedure. Thus the marginal cost of a DES over the BMS is simply the additional cost of a DES over a BMS."

[2] This example is quoted verbatim from Mohindra. R.K. and Hall, J. (2006), "Desmond's non-NICE choice: dilemmas from drug-eluting stents in the affordability gap", *Clinical Ethics*, 1: 82-87.

7. Illustrative scenarios of new funding options

19. Primary care – availability of drugs

- Co-Codamol is a commonly prescribed analgesia in primary care and is obtainable as either an oral tablet or capsule or in effervescent (dissolvable form). A practice of 20,000 patients has 200 patients on effervescent Co-Codamol yet they take other oral medications in tablet form and do not have swallowing problems.
- The cost of a months supply on average of 100 tablets is £8.30 for effervescent Co-Codamol and £7.10 for plain Co-Codamol tablets.[3] The difference in cost per patient is £14.40 per year. If we assume this is a typical practice and apply this cost difference to the whole of UK the figure is approx £8.8 million.
- Patients frequently refuse to swap to plain Co-Codamol because they are used to the effervescent form. Currently most GPs shy away from confrontation with their patients and therefore continue to prescribe the effervescent drug. If the core NHS package of care was defined and drugs such as effervescent Co-Codamol were defined as "non-core" (except for genuine medical reasons), a patient could choose the "core" Co-Codamol at no additional cost or choose to pay £1.20 a month for the effervescent form.
- Currently the NHS has to pay the full extra cost if the GP chooses to prescribe the effervescent tablet. The patient could theoretically obtain a private prescription which would cost about £15 a month including dispensing fee.
- The potential cost saving to the NHS is significant for a minimal or negligible impact on patient care. There are many other drugs which could be handled in a similar way such as enteric coated Aspirin as opposed to plain Aspirin with significant cost savings.

20. Audiology

- Waiting times for hearing aids are very poor with wide variations across the country.[4] Such poor access frustrates patients who have no choice but to receive their services on the NHS because of the very high costs of a privately provided hearing aid.
- The very swift change in the optical services market in the mid-1980s provides a template for reform which would considerably benefit patients. With the introduction of co-payments and vouchers the market moved from largely a monopoly with heavy regulation, little to no competition, no choice, high costs and inconvenient access – much like the current market for hearing

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[3] *British National Formulary*, September 2006.

[4] British Society of Hearing Aid Audiologists (2006), Suffering in Silence 2006, A new survey of NHS hearing aid waiting times conducted by BSHAA.

aids – to a service that is available to all, quickly and at a high quality on the high street.[5]

- Services have been moved out of hospitals and into the community where they are more easily accessible. Prices remained stable and the less well-off – who previously couldn't afford to go private – benefited substantially from improved performance and quick access guaranteed by the taxpayer.[6]
- Such a transformation would be perfectly possible if implemented in audiological services. Deregulation combined with the competition that co-payment would bring would likely improve services. Nor would it come at a high cost. All the improvement in general ophthalmic services occurred over a period when they enjoyed proportionally much slower growth in funding compared to the rest of the NHS. Nearly all improvements in services to NHS patients over the last ten years have in effect been funded by the sector and consumers. Over the long-term, there has been a move from a business dependent on government to one that relies upon consumers for most of its revenues.[7]
- The absolute key point is that audiology services would still remain available to the poorest patients. The taxpayer guarantees access to care for all who needs it, while those that can afford to pay something towards treatment do so. Currently long waits for hearing aids disadvantage the least well-off most who cannot pay for a hearing aid privately, work the system to jump the queue, or afford home care.

[5] Spiers, J. (2003), *Patients power and responsibility.*
[6] Department of Trade and Industry (2004), *Economics Paper No. 9, The benefits from competition: some illustrative UK cases.*
[7] Bosanquet, N. (2006), *Developing a new partnership contract for community eye care in England*, Imperial College London.

8. Future trends

The Government's formal position is that the role of the NHS will expand, with the implication being that extra payments may become unnecessary. Speaking very recently, Patricia Hewitt said:

> "In terms of whether you can define exactly what the NHS will or won't do – that is something the policy review is looking at. But it's not about trying to restrict NHS services to a core offering. What the NHS does continues to grow. GPs will be able to use NHS money for things that would in the past have been seen as social care – [for example] temporary air conditioning in the summer for those with conditions affected by heat."[8]

We believe that this is the wrong assessment of the situation. We would draw attention to the following trends which are increasingly accepted by commentators:

- the pressure on tax-financed healthcare in the UK;
- increases in medical costs; and
- the increasing importance of consumer choice, further encouraged by current steps towards supply-side reform.

The implication of these is that top-up payments will become a more rather than less pressing issue in years to come, in the absence of further funding reform.

Pressure on tax-financing

Since 2000 there has been the largest sustained spending increase in NHS history.[9] This has not prevented the development of the ad hoc mixed funding examples presented above. Given this it is difficult to imagine that further increases in tax-financing on this scale would lead to the elimination of all co-payments.

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[8] *Health Service Journal*, 29 March 2007. This contrasts with her previous statement when she was the Deputy Chair of a Commission looking into healthcare policy: "We are committed to general taxation being maintained as the principal source of funding health services. However we believe it is not possible to expect the continuing gap between resources and demand to be closed through increased tax funding alone. Increased tax funding may play a part, but it seems that the gap will be effectively reduced only by a combination of strategies which include a clearer definition of what services will be provided free at the point of use and raising the proportion of healthcare funding provided by individuals through options such as user charges and /or patient co-payment." Healthcare 2000 (1996), *UK Health and Healthcare Services – Challenges and Policy Options*.

[9] In 2007-08 NHS spending will be £92 billion, which is a rise of over £50 billion since 1999-00 in cash terms. Department of Health (2006), *Public Expenditure on Health and Personal Social Services (memorandum to the House of Commons Health Select Committee)*.

In the current UK context, further increases in tax-financing at the level of the last decade will not be available. Patricia Hewitt has indicated that spending rises in coming years will slow.[10] As a result commentators have spoken of the wedge between public expectations and tax-financing.[11]

This is not to say that efforts should not be made to improve the productivity of the NHS. Clearly they should, both through supply-side and demand-side reform, because the productivity of the NHS during the recent period of spending increases has certainly fallen.[12] There are dramatic gains in output to be achieved for the same or even lower levels of inputs. But it is reasonable to expect that tax-financing will continue to struggle to provide a universal service even given dramatic improvements in productivity.

Lastly the ageing of the population is also relevant. As well as supply and demand, the other fundamental divide is between consumer demand and society's need. As medicine advances and the population ages, consumers will inevitably want to spend more than society wishes to fund. In coming years numbers of young taxpayers will fall relative to the older generations. Will the young taxpayers of 2016 or 2026 wish to fund the health wishes of a much greater number of non-taxpayers?

Increases in medical costs

Improvements in medical technology will increase the upwards pressure on costs. The Government has sought to downplay such arguments by suggesting that technology has not accounted for a large proportion of rising health spending.[13] But the evidence is strong:

- in its review of intergenerational finances, the Australian Government has estimated that around two-thirds of extra health spending is due to new technology and treatments. As a result taxpayer-funded spending had more

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[10] Speaking to the *Financial Times* on 29 March 2007, the Secretary of State for Health said that she expected that the NHS "will continue to grow, and grow faster than the rate of economic growth generally". Responding to whether this meant a 3 per cent growth, she said: "That is your deduction, but I am not dissenting from it." Real terms spending increases have been roughly 7 per cent per annum in recent years.

[11] Bosanquet, N., de Zoete, H. & Haldenby, A. (2007), *NHS reform – the empire strikes back*, Reform; BUPA, NERA and Frontier Economics (2006), *Mind the gap: sustaining improvements in the NHS beyond 2008*.

[12] The King's Fund (2005 & 2006) and a study by the Health Foundation (2006) have noted how roughly three-quarters of the increased spending each year has gone into costs. Authors of the Health Foundation report, Stephen Martin and Peter C Smith of the University of York and Sheila Leatherman of the University of California, said: "the impact of these cost pressures means that much less money is available for increased activity, which is the prime driver of NHS output".

[13] HM Treasury (2006), *Long-term opportunities and challenges facing the UK: analysis for the 2007 CSR*.

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than doubled (to 4.0 per cent of GDP) in 2001-02; it was projected to double again by 2041-2;[14]

- the Congressional Budget Office has estimated that all factors – including technological advance – may increase federal spending on Medicare and Medicaid to 12.5 per cent of GDP in 2050 compared to 5.0 per cent in 2010;[15] and
- a study by one of the authors of this paper estimated that the cost per cancer patient per year will rise from £20,000 today to £100,000 in 2025.[16]

A crucial way in which technology puts upwards pressure on costs is through improvements in survival.[17] In the next quarter of a century medical advances will mean that cancer will become a manageable condition rather than a major risk of premature death or severe disability.[18]

The changing incidence of disease and society will also play their part. Many commentators have drawn attention, for example, to the increasing incidence of obesity and its related illnesses, diabetes and mental ill health.[19] The Department of Health has noted how in estimates of disease burdens, mental ill health is second only to cardiovascular disease in disability adjusted life years above more traditional diseases such as cancer and respiratory illness.[20]

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[14] Commonwealth Australia (2002), *Intergenerational Report*.
[15] Congressional Budget Office (2005), *The Long-Term Budget Outlook*.
[16] Sikora, K. (2004), "Cancer 2025: The future of cancer care", *Expert Review of Anticancer Therapy*, 4(3), Suppl.
[17] Siemens Financial Services (2006), *Healthcare Affordability – the Global Challenge*. "The relative pressures of demographic change, with proportionately more elderly people (high healthcare consumers) and fewer working age people (who tend to be net contributors to their health services), are universal to all the countries we studied. Additionally, modern, relatively sedentary lifestyles and creeping obesity have led to increasingly early manifestation of diseases such as coronary conditions. Meanwhile the progress of drug treatments has made it possible to keep people alive for longer. All these factors tend to lead to higher healthcare consumption. Moreover, they provide financial challenges that must be dealt with in the short term."
[18] Bosanquet, N. & Sikora, K. (2006), *The Economics of Cancer Care*, 2006. "Cancer will become a chronic, controllable illness rather like diabetes or hypertension today …. People living with cancer will receive care in an attractive hotel-like environment rather than a hospital, run by competing private sector providers. Global franchises will emerge using the web to disseminate treatment plans and control their quality."
[19] For obesity, see Department of Health (2006), *Forecasting Obesity to 2010*. For diabetes, see All Parliamentary Group for Diabetes and Diabetes UK (2006), *Diabetes and the disadvantaged: reducing health inequalities in the UK*. For mental health, see Layard, R. (2004), *Mental health: Britain's biggest social problem?*, Cabinet Office; and Alzheimer's Society (2007), *Dementia UK*.
[20] Department of Health (2004), *The NHS Improvement Plan, Putting people at the heart of public services*.

Consumer choice

But potentially the most important driver of change is social rather than economic in nature. As society has become richer it has become more empowered. As the former Secretary of State for Health, Rt Hon Alan Milburn, has said: "We live in an individualist, consumer world now, whether we like it or not."[21]

As patients become more and more used to choice, diversity and instant access in other areas of their lives they will demand more from healthcare (especially as they see more of their money being spent on it). Information about different types of drugs, treatment and care is much more widely available than it was just 10 years ago.

A key factor here is the supply-side reforms that are currently under development in the NHS in England. The progress of the reforms has been uncertain but it remains a possibility that a new NHS "market" could emerge giving some new choices to patients, including voluntary and for-profit providers. If this does happen, a greater variety of supply will hugely increase the likelihood of new kinds of demand. On the one hand, new providers will put forward innovative new services. On the other, successful supply side reform is likely to run into new problems of rationing as improvements increase the demand for services.

Legal situation on top-up payments

Top-up payments are legal within current legislation, even though the mechanisms for their provision are not fully established.

The General Medical Council's view is that the first duty of a doctor is to his patient. Thus if there is a beneficial treatment available, even if not provided by the NHS, then it becomes the doctor's duty to inform the patient of the situation. Furthermore if the patient chooses to pursue the treatment option then the doctor should take all reasonable steps to procure it in the most efficient manner possible.[22]

The days of "doctor knows best" are over. Indeed, the GMC places a responsibility on a doctor to consider what is in the patient's best interest in advising them about the options, implicit in this statement is that if a clearly better treatment were not available on the NHS, this should still be discussed:

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[21] *The Independent*, 27 September 2003.

[22] "The duties of a doctor registered with the General Medical Council. Patients must be able to trust doctors with their lives and health. To justify that trust you must show respect for human life and you must: Make the care of your patient your first concern …. Give patients the information they want or need in a way they can understand. Respect patients' right to reach decisions with you about their treatment and care." General Medical Council, *Duties of a doctor*. Available at www.gmc-uk.org.

"The investigation or treatment you provide or arrange must be based on the assessment you and the patient make of their priorities, and on your clinical judgement about the likely effectiveness of the treatment options."[23]

To prevent doctors abusing their NHS position – essentially to tout for private practice – a series of complex rules have been created within the National Health Service Act 1977. This Act states that services must be provided free of charge except where the making of charges is expressly provided for and that a patient cannot be both a private and a NHS patient during a single visit to a NHS organisation. The British Medical Association's Code of Practice states that patients who choose to be treated privately are entitled to NHS services on exactly the same basis of clinical need as any other patient although emphasises that patients cannot be both private and NHS at the same consultation. This is reiterated in the NHS Code of Conduct for Private Practice.

After a careful study of the background documents a leading counsel, acting on behalf of a medical insurer, concluded that there was no reason why patients should not move between private and NHS treatment and that there was no bar in law to a patient buying his own drugs or devices and having them administered as part of a course of NHS treatment.[24]

[23] General Medical Council (2006), *Good Medical Practice.*
[24] Personal communication to Karol Sikora.

9. Equity

It is widely understood that the NHS does not provide healthcare on an equitable basis to different income groups.[25] The issue of top up payments also bears on this discussion.

Even with current improvements in waiting times healthcare is often rationed by waiting especially in unpopular and untargeted diseases.[26] This is profoundly inequitable since the better off are able to avoid delays either through articulation or by accessing private treatment. In addition sufferers' conditions worsen while they are on the waiting list.[27] There are also issues regarding differing levels of entitlement to care across the country. In some parts of the country a PCT will fund a treatment while in others they will not. PCTs do not have to fund NICE recommendations thereby exacerbating the "postcode lottery".

But it is clearly the case that an unregulated system of co-payments – as shown in the case studies – is also inequitable too. We run the risk of achieving the worst of all worlds: inequitable NHS provision combined with inequitable provision outside of the service. In both worlds the least well-off are disadvantaged.

As the range of services has increased these equity and access problems have become more rather than less difficult. We need a review of the options on how to improve access in what in effect is becoming a mixed economy of healthcare with many elements of inequity.

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[25] Professor Julian Le Grand of the London School of Economics has shown that following a heart attack, intervention rates of coronary artery bypass grafts or angiography are 30 per cent lower in the lowest socioeconomic groups than in the highest. Le Grand, J. (2006), *The Blair Legacy? Choice and Competition in Public Services*, lecture to the London School of Economics. Another study has shown that while need for hip and knee joint replacements were three times as high in the poorest quintile of the population than the wealthiest quintile, the number of operations were no more common. Steel, N., Melzer, D., Gardener, E. & McWilliams, B. (2006), "Need for and receipt of hip and knee replacements – a national population survey", *Rheumatology*; 45: 1437-1441.

[26] For example the latest British Society of Hearing Aid Audiologists survey into hearing aid waiting times found that the average wait facing someone seeking their first NHS hearing instrument in England had risen for the third year in a row to between 45 and 48 weeks (compared with 43-47 weeks in 2005). There are wide variations across the country with patients waiting on average between 73 and 74 weeks in the South East. Four hospitals in England have waiting times of 117 weeks, that's 2 years and 3 months, the longest waits in the UK. British Society of Hearing Aid Audiologists (2006), *Suffering in Silence 2006, A new survey of NHS hearing aid waiting times conducted by BSHAA*. For further information on poorly performing areas of the NHS see Bosanquet, N., de Zoete, H. & Haldenby, A. (2007), *NHS reform – the empire strikes back*, Reform.

[27] For example, one study found that 21 per cent of lung cancer patients became unsuitable for curative treatment during the wait for their radiotherapy. O'Rourke, N., Edwards, R. (2000), "Lung cancer waiting times and tumour growth", *Clinical Oncology*, 2000, 12: 141-144.

10. Conclusion

We have presented evidence that NHS patients are routinely seeking options to top-up their NHS entitlement in order to access new kinds of care, faster access and higher quality. We have also described key trends, widely accepted among healthcare commentators, that suggest that such payments will become more rather than less prevalent over time. Yet at present the issue of "top-up" payment and indeed funding reform remains a taboo in frontline politics.

We would reiterate that the costs of this approach in terms of equity are great and becoming greater. For the same reason the benefits to an open debate about funding mechanisms are very great. Doctors must play a major role in this.

This debate should be based on the fundamental NHS principle that care should be universally and equitably available. We would also suggest that the debate may well be helped by a discussion of what would entail an NHS core service.

Increasingly some influential politicians are willing to confront the issues of health funding reform.[28] The public are already using top-up payments to get round perceived blocks in the NHS. The mirage of a service completely free at

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[28] Dorrell, S. (2005), *Hansard*, 24 May 2005, col. 592. "Reform of the public services involves reassessing the balance between individual and collective responsibility, and accepting that some matters that were regarded in the post-war world as the responsibilities of the taxpayer will increasingly have to be regarded as responsibilities that the individual at least shares with the taxpayers .... I end with a rhetorical question: does anybody seriously believe that the issues I have raised in connection with dentistry and universities are unique to those services?" Laws, D., (2004), "UK health services: a Liberal agenda for reform", *The Orange Book*. "This country should be looking at some of the experiences of those European nations who succeed in delivering health services of greater choice and competition than our own, but also with better health outcomes and fairer access for lower income groups .... Indeed, only such a radical reform of the funding and organisation of our health services is likely to deliver a high quality of services for those on lower incomes – who are presently those who pay the highest price for NHS failure." See also House of Commons Health Select Committee (2006), *NHS Charges*. "In the future, the NHS may not be able to pay for every possible medical treatment in a country with an ageing population, demographic pressures, rising public expectations and increased possibilities of medical treatment and long-term therapies. Some treatments or procedures may have to be charged for …. The Government should consider this possibility sooner rather than later to ensure that a set of consistent criteria apply to those areas for which a fee is charged, to avoid the development of charges in an ad hoc way, as has been the case until now." See also Charles Clarke speech on 7 February 2007 at the London School of Economics. "I do not believe that over the coming decades the combination of Gershon-type efficiency gains and the likely levels of increased allocations from the Treasury are likely to meet public expectations, and the consequent political pressures. The only way out of the dilemma which governments will therefore face is to permit some levels of charging, along the lines of university tuition fees."

the point of delivery is rapidly fading. Patients need political and medical leaders to join the debate.

It has to be recognised that the use of top-up payments is increasing but on an ad hoc and dispersed basis. We need to face up to this rather than ignore it. We need a more realistic debate than politicians of all parties are willing to allow on how to define core services and the role of top-up payments.

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