‘Top up payments and NHS funded Cancer care’
An RCN response to the review of the consequences of additional private drugs for NHS care

Executive summary

With a membership of over 390,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world.

RCN members work in a variety of hospital and community settings in the NHS and the independent sector. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

In preparing this response the RCN has consulted its members, many of whom are specialists in the field of cancer nursing. This response to the review is not intended to be exhaustive – the issues being raised are far too complex to capture in one submission.

The RCN’s submission is written so as to respond directly to the terms of reference to the review.

1. To examine current policy relating to patients who choose to pay privately for drugs that are not funded on the NHS and who, as a result, are required to pay for the care that they would otherwise have received free on the NHS.

2. To make recommendations on whether and how policy or guidance could be clarified or improved.

3. In making recommendations, to take into account:
   a. the importance of enabling patients to have choice and personal control over their healthcare; and
   b. the need to uphold the founding principle of the NHS that treatment is based on clinical need not ability to pay, and to ensure that NHS services are fair to both patients and taxpayers.

In making its response the RCN has also taken care to put its evidence in light of the Government’s wider strategy for improving the quality and effectiveness of NHS services; and developing policy and practice arising from the NHS Next Stage Review and Constitution.
The RCN has pointed out previously the progression of the rhetoric and reality of choice in the NHS and highlighted concerns that consumerism in health care will bring consequences for nurses, patients and policy makers which must be carefully thought through\(^1\).

Such choice, if not properly deliberated, has the potential to exacerbate inequalities as the public make choices others are not able to make. In this case, there is a clear risk of creating a ‘Business class’ standard of cancer care for those who have the money, whilst the rest would have to be content with the relative discomfort of the ordinary traveller.

In short, the reality is that people have been topping up NHS care for years. We are already able to buy hearing aids, orthopaedic braces, wheel chairs and other mobility aids, eye care, dental care and even nursing care all whilst receiving some element of NHS-funded care. What lessons have been learnt from policy makers all this time? In particular, what has been learnt from the funding of long term care?

It is unfortunate that so little time has been given to explore the important issues this review raises. There is already stark inequality of access to some services, a bewildering array of different co-payments and top-ups that can be made and without proper reflection and study of the whole picture we are in danger of failing to learn the lessons of the previous ten years.

However, taking into account the short time frame given, the RCN is making the following recommendations to the review:

1. Given the potential for the withdrawal of care and the potential for suffering being prolonged, Government should allow ‘top up’ payments for private prescriptions alongside funded NHS care for a time limited period in order to publicly work through the wider implications of this issue.

2. During this time, Primary Care Trust (PCT) ‘exemption’ request processes for unapproved drugs and treatments needs to be urgently reviewed and mandatory national guidance drawn up which enshrines effective clinical engagement, improves public accountability and which addresses the gross inequalities in entitlement the current system produces.

3. NICE has made a significant impact on the NHS. However, that work and the remit of NICE need to be publicly explored and a new consensus obtained for the use of economic modelling in the allocation of NHS resources. Attention should be paid in the meantime to enhancing transparency of decision making and speeding up authorisations processes.

4. The role of NICE must also be considered in light of the concerns raised by the Health Committee in 2007. In particular, it was recommended that the threshold for the Quality Adjusted Life Year (QuALY) should be reviewed.

particularly as there is no empirical basis for the current limit\(^2\). The demand for NHS services will always exceed supply and the RCN recognises that not every treatment can be provided to every person. NICE has a vital role to play in assisting with the allocation of resources and, with the support of Government, should make clear to the public how and why such decisions are made.

5. It is the RCN’s view that the whole purpose and use of co-payments and top up payments where they exist should be reviewed with a view to establishing what is and what is not funded by the NHS.

Royal College of Nursing
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Introduction

Unequal provision of NHS resources is a reality for thousands of people every day. A large section of the population already experience difficulty in accessing treatments because of their social status or physical and mental abilities, or simply because the process for obtaining funded care is bureaucratic and inaccessible. The appalling state of affairs surrounding the authorisation of long term care costs should be a sobering reminder that cancer care is not the only area that needs such high level political and professional attention.

In respect of allowing patients to top up NHS cancer care with private monies for drugs, the RCN notes the current position as detailed in DH guidance in 2003 and again in 2004\(^3\). It is surprising to note that this important issue is covered under a very small part of guidance aimed at guiding Trusts and Clinicians in managing private practice in the NHS. This position was eloquently restated by the Rt. Hon Alan Johnson in the House\(^4\)

> “Someone is either a private patient or an NHS patient. They can be a private patient and decide to resume their treatment as an NHS patient, but they cannot, in one episode of treatment, be treated on the NHS and then allowed, as part of the same episode and the same treatment, to pay money for more drugs.”

In addition to the above summary we believe it is also important to clarify terms. For the public and some parts of the media, words like ‘co-payments’ and ‘top-ups’ are used interchangeably but we believe that this clouds several distinct issues.

Co-payments may be defined as a financial contribution to the overall costs of providing products or services. In countries such as France, Germany and so on, those payments raise only a small proportion of the total costs of care. In NHS England such co-payments already exist in the NHS – for e.g. prescription charges, dental charges, and so on. Clearly the prescription charge bears no resemblance to the actual cost of providing the individual prescription but is instead seen as a contribution which helps with the overall costs.

However we consider that a ‘top-up payment’, particularly in the context of this review, is a payment made to purchase products or services \textit{in addition} to those already provided under the NHS. For example, it has long been the case that NHS patients can buy a more expensive type of hearing aid privately but have both the testing and the fitting of the device carried out by the NHS. At a recent BMA conference a consultant orthopaedic surgeon stated that he regularly treats patients for sports injuries who pay for physiotherapy or sports braces privately\(^5\). Some NHS hospitals also allow women to pay to secure a one-to-one midwife during labour\(^6\).

\(^3\) DH guidance on private income etc
\(^4\) Hansard 17 June 2008 Oral Answers to Questions to the Secretary of State for Health
\(^5\) The Sunday Times (2008) ‘We’ve paid into the system all our lives. Why has the NHS turned on us?’
\(^6\) See for example the Jentle Midwifery scheme at Queen Charlotte’s and Chelsea hospitals NHS Trust
Whilst accepting that some may consider the above distinction semantics, we believe it raises an important question which is not being addressed by the Review but which must be answered – what is the impact of the current system of co-payments and ‘top-up payments’ in terms of the broad objectives of the NHS? To what degree do prescription charges, dental charges, and most significantly, charges for long term care impact upon the wider equality goals of the NHS?

It is this question which we believe should be asked before developing further policies which may or may not undermine the principle of the National Health Service.

The following section proposes key areas for policy clarification and development on the issue of top-up payments in cancer care and its wider implications for policy.

**Top-up payments**

There are two main issues we wish to explore in our submission
- Existing approval processes for NHS drugs and care
- Impact of accepting or rejecting top up payments in cancer care

**Existing approval processes for NHS drugs and care**

The evidence we have received from our members suggests that the one cause of unhappiness amongst the public who have genuinely enquired about different treatment options available to them is the manner in which the enquiries have been handled by Primary Care Trusts (PCTs).

Some PCTs appear to have a robust process for dealing with requests for unapproved drugs or therapies – often called ‘exemption’ requests – which are publicly accessible and give a clear statement of principles upon which any decision will be based.

Of particular importance would be the role of the PCT in justifying public confidence that the decision has been clinically driven as well as financially informed. Currently, we understand that PCTs do not have to spell out what is meant by ‘exceptional circumstances’ provided the policy genuinely recognises the possibility of there being an overriding clinical need and provides for each request to be considered on its own merit.

We note that in the case Rogers v. Swindon PCT\(^7\) the court decided it was permissible for a PCT to carry out a cost/benefit analysis when deciding what treatments to fund. Set against the legal requirement for PCTs to break even, it is clear that PCTs are required to consider the cost of all treatments before agreeing to fund them.

The public however are unlikely to be moved by the financial requirements of PCTs – bodies which exist entirely to serve the public and are paid for by public funds. The surviving partner of Mrs O’Boyle who died from cancer after paying for a private prescription and for all her NHS treatment as a result of a refused exemption request put it like this;

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\(^7\) [2006] EWCA Civ 392, [2006] All ER (D) 181 (Apr)
“She knew and I knew she was not going to get better but if there was the possibility of spending more time with her four young grandchildren, to see them grow up a bit more, we wanted to take it”

If it is accepted publicly that decisions like this should be made by PCTs on behalf of the public, staff responsible for making such decisions need to be confident that they do so with the backing of Government, the professions, the media and indeed, the public. As such, these decisions need to be based on the highest possible degree of public, professional and human scrutiny.

We believe that it is vitally important that clinical judgement, accurate weighing of evidence and due consideration of the implications for the patient in question should top the list of considerations rather than cost, although we recognise that this is important.

Allowing a patient’s exception request has implications beyond simply paying for the drug. In the case of ‘Trastuzumab’ (Herceptin), we understand that additional clinical tests, staff development and changes to policies and procedures all impacted upon resource allocations beyond the cost of funding the drug itself\(^8,9,10\). In addition, in the event of an adverse reaction to an exempted drug or treatment, the costs of emergency or critical care can be substantial.

Similarly, the implications for a refusal to fund treatment go beyond cold appraisal of the facts or a de facto affordability argument. A decision to refuse to fund treatment for a person in fear for their life or indeed fearing a painful or debilitating death has a profound impact on the person concerned, their families and on society as a whole.

Before developing policy in the area of ‘top up’ payments, it would seem appropriate to spend some time urgently reviewing two things:

Firstly, the public debate around mechanisms for allocation or resources (or to put it bluntly, rationing) needs revisiting in light of the profound implications this review could raise for the NHS and the public it serves

Secondly, existing practice amongst PCTs for dealing with exemption requests needs to be urgently audited and reviewed. National guidelines should be drawn up on how PCTs should conduct themselves when faced with such exemption requests. This needs to be followed at regular intervals by robust audits of all decisions and an informed evaluation of the impact of the acceptance or denial of exemption requests.

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\(^8\) Guardian June 2\(^{nd}\) 2008

\(^9\) In the case Rogers v Swindon PCT it was identified that Herceptin is given by a loading dose followed by a further 17 doses given at three week intervals. The estimated cost (including VAT) of the course of treatment was £ 26,328.22, which Mrs Rogers was unable to pay. This included operational costs, screening and the drug itself.

\(^10\) In an article in the BMJ specialist clinicians estimated drug costs alone for one NHS Trust would be £1.9m and when added to the cost of administration and operation, would lead to the closure of other services – see Barrett, A et al (2006) ‘How much will Herceptin really cost?’ BMJ 333:1118-1120 (25 November)
In this way we would hope future policy would be informed by concrete data based on the experiences of real people in times of real need.

Having re-established exemption processes, and ensured that PCTs had both the support and the capacity to make such difficult decisions, it would then be important to take a look at the role of NICE in approving drugs and treatments to address a considerable concern raised in our consultation – the length of time in approving drugs or treatments.

This has already been addressed to an extent in recent ministerial announcements but it is worth stating again. If the country has accepted in full the need for a model of economic determination for the rationing of limited NHS resources, such processes need to uphold the highest levels of public accountability, scrutiny and integrity.

The impact of accepting or rejecting top up payments in cancer care

If top up payments are \textit{not} allowed to be made alongside free NHS care then there is in effect a \textit{withdrawal} of care from the patient on the basis that the requirement to pay for the full package of care would put treatment beyond the reach of many.

This cannot be accepted and must be remedied immediately in the \textit{short term} by allowing private prescriptions in cancer care alongside funded NHS care. During this time there should be a thorough review and consideration of the wider implications of prolonging this practice.

If, as a result of this review, Government policy were to move towards accepting the use of private money in topping up NHS care, there are several issues to think through.

\textit{A two tier system} – if policy were to be reviewed to allow for private prescriptions to be combined with free NHS care, this would have profound implications on the equity of the NHS. Not only would there be a level of care which would in effect be unavailable to the poorest, but time spent on therapies for the few which are unavailable to the many would divert resources from the NHS to essentially an exclusive service for those able to pay. In effect, the NHS would be providing a ‘Business Class’ service to those who could pay, whilst the rest would have to be content with the relative discomfort of the ordinary traveller.

Any attempt to address such financially based inequality through instituting means testing or some form of prior assessment to ascertain entitlement to financial support would require a bureaucracy of considerable proportion. This in itself would be a drain on resources and will have with it all the weaknesses of means testing we already know.

\textit{NHS Constitution} – the current consultation on the constitution would have to be amended or some form of words added to capture this significant change in the character of the NHS. It is entirely possible that the founding principles of the NHS would have to be reviewed in light of a decision to allow top up payments.
Standards and availability of health information - the industry in health care information is growing rapidly as is the market for new drugs to treat a range of conditions. Information about those developments is more readily available on-line and at times, commercial or pre-license information can appear as impartial clinical advice, which can distort decision making and provide false hope for some patients. The media must also share some responsibility for this situation and consider their role in reporting new developments. David Taylor (MP) makes this point;

“Desperately ill patients and their families are vulnerable to the false hope provided by miracle drugs which are sometimes touted by the media”\textsuperscript{11}

In effect there also exists a section of the population who live in information poverty and who cannot access up to date health information due to personal ability or circumstances. Opportunity to explore treatment alternatives would have to be made available for those who have difficulty accessing information.

Conclusions

The RCN is of the view that the scope of this review is not wide enough, nor the time given for it long enough. The implications of a move in either direction are profound and require much more careful consideration.

The inequity which prompted this review already exists in a range of settings – long term care, social care, audiology, access to dental services and so on. It is the RCN’s view that the whole purpose and use of co-payments and top up payments, where they exist, should be reviewed with a view to re-establishing the principle of an NHS free for all at the point of delivery.

Whilst this review takes place and to prevent further avoidable suffering, ‘top up’ payments should be allowed for a time limited period. Whilst we recognise the resource implications of this decision for the NHS, it is inconceivable that a Government which has worked so hard to develop and improve the NHS for all would allow a system of preferential treatment to be instituted for those who can afford to pay.

In the short term, and before embarking on further debate about top ups, the process by which PCTs respond to exemption requests for normally unfunded care needs to be urgently reviewed and improved. There are a number of judicial challenges to this process every year which are invariably settled out of court save for one or two notable exceptions. It would be essential, in the RCN’s view, for this process to be reviewed and guidance for PCTs to be issued which

- Enhances transparency and accountability
- Improves clinical engagement in the process
- Increases public confidence

\textsuperscript{11} Hansard 18 Dec 2007 : Column 716
The role of NICE could be enhanced to incorporate consideration of applications for ‘top up’ payments as suggested by the IPPR\textsuperscript{12}. For example they could have a role in assisting PCTs in any ‘exemptions’ decision making processes where NICE have not already ruled or where there is a newly emerging or disputed clinical evidence base. However, this would be an additional role for an organisation already heavily committed to expanding its role and speeding up its processes. Such moves should be carefully considered as part of a longer term plan and should arise out of a public decision to endorse the general approach i.e. that a cost value basis is the right way to ration limited resources within the NHS.

In the long term, the reality is that the funding of the NHS may well have to be increased but before that the methods of determining resource allocation must be improved to enable us to accurately establish how much extra resources should be allocated to whom and why.

A public debate about the priority of the Nation’s health service and the continued use of economic modelling to determine entitlement should be facilitated and policy amended to reflect the outcomes.

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\textsuperscript{12} Farrington-Douglas, J and J Crabtree (2008) ‘Topping up: Should it be allowed in the NHS?’ NHS Confederation Debate Papers - 17 June