

RATIONING IN THE NHS

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As part of our role to deliver evidence to support better health policy, the Nuffield Trust aims to help the three main political parties weigh the evidence as they draft their General Election manifestos, outlining what we believe to be the most important issues.


We are producing a series of policy briefings on the issues and challenges we believe are critical to the longer-term success of the health and social care system, and which any new administration following the election will need to prioritise.

This briefing is the second in our series – it focuses on the issue of rationing health care. The first briefing from the series examined the state of general practice.

Alongside our policy papers, we are regularly surveying a panel of 100 health and social care leaders in England for their views on a range of issues, including the state of the NHS and social care system, and what they believe should be the priority areas for reform during the next Parliament. Our latest survey is also on the topic of rationing health care and is published alongside this briefing. The survey results provide useful insights for policy-makers into the views of leaders as we approach the election.

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NO ONE LIKES DISCUSSING RATIONING, but all health systems operate some form of it whether by using waiting lists, ability to pay, setting explicit lists of what is and is not available, or limiting resources and leaving difficult decisions to clinicians.

Access to expensive drugs and treatments, restrictions on surgery, waiting times and postcode variation in what is provided are issues of significant concern to the public. The rationing question is more likely to arise now the NHS has had its budget held roughly flat in real terms since 2010/11, during a period where the population has been growing and ageing rapidly, and the range of new and expensive treatments continues to expand. This is a contested area with no easy solutions.

This briefing, part of a series from the Nuffield Trust ahead of the General Election, sets out our views in response to some questions:

- What are public attitudes to rationing?
- How are rationing decisions made?
- How much explicit rationing is there and how might this change?
- Is NICE working and could its role be extended?
- What is the verdict on the Cancer Drugs Fund?
- How much money can rationing save?
- What are the messages for policy-makers from this?

KEY POINTS

Rationing is taking place whether we like it or not – the question is the degree of transparency surrounding approaches used to ration care.

There is scope to improve the level of transparency in the system, particularly at the level of local commissioners; to use public consultation more effectively and consistently; and to communicate better the dilemmas faced by decision-makers.

There is a need to be clear about what the rules are: what it is permissible for a clinical commissioning group to do in varying what is offered; what they have to demonstrate in terms of public involvement and the rational basis of their decision; and what national leaders consider to be ‘acceptable variation’.

There is a tension between the role of politicians at the national level in helping to shape the landscape within which rationing decisions are taken and their duty to speak up for their local constituents. Intervening in individual commissioning decisions can be particularly problematic if it undermines the legitimacy of the decision-making process that successive governments have put in place.

The National Institute for Health and Care Excellence’s (NICE) approach to appraising new technologies is internationally admired. But the NHS is only required by government to adhere to some of NICE’s recommendations. Making it compulsory to follow all NICE guidance would not solve the problem of how to allocate resources between programmes, as providing everything the guidance requires for an area would almost certainly be unaffordable.

To date, the rationing process has been one of muddling through, with some approaches based on more transparent principles at the margins. As financial pressures increase, the legitimacy of some approaches, such as restricting access to surgery for financial reasons, using clinical criteria, and the Cancer Drugs Fund, will face greater scrutiny.

Given the lack of evidence to justify the existence of the Cancer Drugs Fund, and the challenges to the wider system posed by the fund, we believe that NICE should resume responsibility for making decisions about the availability of cancer drugs.

INTRODUCTION

This briefing sets out to highlight some of the key issues and dilemmas facing policy-makers and practitioners in the area of rationing. It does not attempt to be comprehensive, but is intended to be a useful appraisal of current approaches to rationing for Members of Parliament (current and prospective).

The paper puts forward some ideas and views that we believe should be taken into account when considering how rationing decisions are made in the NHS. It is also informed by literature in this field and by an analysis we have undertaken into the nine publicly available sets of policies covering a non-representative selection of 15 clinical commissioning groups (CCGs). These cover a mix of both urban and rural areas, as well as different levels of deprivation.

‘Trade-offs and compromises are inevitable and attempts to avoid making rationing decisions are common’

The key message is that rationing is a fraught and difficult area with no easy answers. Decisions can only be made on an objective and scientific basis up to a point, as they embody societal and personal values which are often fundamentally irreconcilable and sometimes not consistent over time or between different cases. Trade-offs and compromises are inevitable and attempts to avoid making rationing decisions are common. We can, however, do better at avoiding the worst of the fudges and some common errors, including assuming that rationing some treatments will make a significant difference to NHS finances, or that there are satisfactory technical answers that will remove postcode variation without unintended consequences.

Politicians play a significant role in determining the values underpinning the system at its highest level. For instance, the current system dividing local and national commissioning between CCGs and NHS England was designed by the Coalition Government, and the introduction of an institute to determine effectiveness was first mooted by John Major’s Conservative Government, with the National Institute for Clinical Excellence (NICE; now called the National Institute for Health and Care Excellence) subsequently being introduced by Labour.

However, there is tension between the role of politicians at the national level – for example, in shaping the framework within which local commissioners operate and the autonomy they have to tailor the treatments and services they provide – and the role of politicians at a local constituency level, in which they may disagree with some specific funding decisions of their local CCG.

Politicians therefore can help to shape the landscape within which rationing decisions are taken, but in the UK, as in most countries, they try to remain at least one step removed. Intervening in individual commissioning decisions can be particularly problematic if it undermines the legitimacy of this decision-making process.

WHAT ARE PUBLIC ATTITUDES TO RATIONING?

The public appear to be ambivalent about how funding pressures should be handled in the NHS. In polling by Ipsos MORI conducted in winter 2013, 51 per cent of people agreed with the statement ‘there should always be limits on what is spent in the NHS’.¹

On drugs spending, only 28 per cent of respondents to a 2006 Ipsos MORI poll said that value for money should be the basis for decisions; the other 72 per cent believed that cost should not be an issue, and 31 per cent of these thought the NHS should provide all drugs and treatments no matter what they cost. The public also dislike postcode variation – 73 per cent of respondents to an Ipsos MORI survey in 2008 supported the view that treatments on the NHS should only be available if they are available to everyone.²

One way to lessen the extent of postcode variation would be to boost NHS funding through increased taxation, but again, public opinion about this is mixed. Thirty-eight per cent of respondents to the 2012 British Social Attitudes survey told researchers they would pay more tax in order to improve the level of health care ‘for all people in Britain’, while 31 per cent said they would not.³

HOW ARE RATIONING DECISIONS MADE?

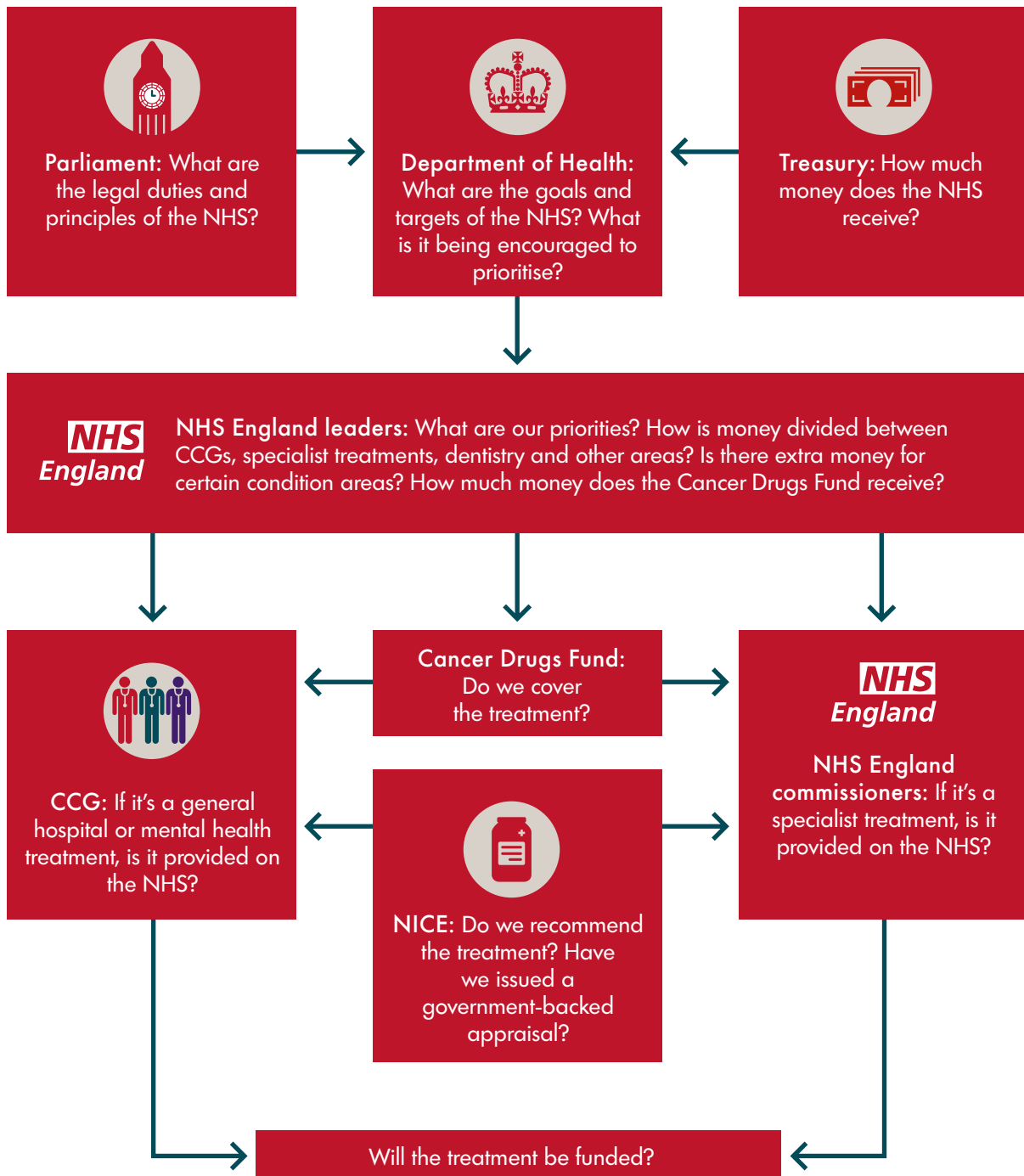
The UK has not adopted the approach of defining a list of services that should or should not be provided, as found in some other countries (the benefits and challenges of this approach are explored in more detail in the Nuffield Trust’s *Rationing Health Care: Is it time to set out more clearly what is funded by the NHS?*⁴).

The closest the NHS gets to any public statement of entitlement is contained in the NHS Constitution, which states that patients in England have the right to:

- access NHS services based on clinical need
- be treated within some maximum waiting times
- access drugs and treatments recommended by NICE, if a doctor says it is appropriate
- expect local decisions to be made rationally, following a proper consideration of the evidence.

Clinicians make most decisions about what treatments are offered to patients based on their assessment of the patient’s needs. This is informed by research, professional bodies and, where applicable, NICE. Some clinicians, for instance GPs, are expected to make decisions in the context of finite resources: every decision to admit a patient or prescribe

FIGURE 1: NHS RATIONING: WHO DECIDES WHAT?



a drug means that money cannot be spent on something else. By their nature, decisions about whether or not to refer a patient are a matter of an individual clinician’s professional judgement. Differences between clinicians’ referral patterns and treatment practices are likely to be one of the causes of variation between areas in the use of particular treatments and procedures.

CCGs set the amount of funding available for the treatments and services they commission, with NHS England being responsible for specialist

services. These decisions are based on a combination of local needs assessment, national priorities, guidance from NICE and professional bodies and, to a significant degree it appears, the legacy of previous spending decisions⁵. There is no satisfactory methodology that allows a way of allocating resources across different programmes of care in a purely objective or scientific way. NICE is able to use a more explicit approach, but this is because it is generally considering one treatment or area of care at a time – this is explored in more detail below.

Only some of these processes are subject to transparent, evidence-based decision-making: a wide range of NHS bodies at national and local levels have underpinning ethical principles which they deploy with varying degrees of transparency and public accountability, as we explain below. The question is how consistently the principles are applied or departed from by different agencies. For the many decisions that fall outside these rational and transparent rationing processes, how feasible might it be to bring more of them into public scrutiny?

HOW MUCH EXPLICIT RATIONING IS NOW TAKING PLACE?

As explained above, many of the decisions about whether to offer treatment are implicit, individual and, by their nature, not transparent. There are, however, increasing numbers of examples where commissioners have been making more explicit choices to limit or exclude some treatments. There is no comprehensive survey of this so we have examined practice in commissioning documents covering a non-representative sample of 15 CCGs and used data from a number of sources.

There is some consensus among commissioning organisations in general around a list of low value interventions, which includes some cosmetic procedures; some that are relatively ineffective; some where the procedure is effective but there are more cost-effective alternatives; and some where there is a close risk/benefit balance in some cases.⁶ This is sometimes referred to as the ‘Croydon list’ after the primary care trust that developed it.

Decisions are just as difficult, and vary more, where procedures might affect people’s major life events, or relieve pain or discomfort, but are not deemed by commissioners to be of high enough priority. For instance, NICE recommends three full cycles of IVF for women aged under 40 who have failed to get pregnant after two years of trying, and one full cycle for some women aged 40-42.⁷ But research by fertility charity Fertility Fairness using freedom of information responses found that more than 80 per cent of CCGs were failing to commission three full cycles of IVF, in line with NICE guidance, with only 38 offering three full cycles and one, Vale of York CCG, offering none.⁸

NICE recommends when people should and should not receive treatment, but its general guidance (in contrast with its technology appraisals) is not

binding. In 2011, it issued new recommendations that women should receive caesarean sections on request, even with no clinical need, as long as they are fully informed and a set of alternatives have been exhausted.⁹ Yet several CCG policies that we reviewed do not reflect this. West Lancashire and Wiltshire are examples of CCGs which as a rule do not fund caesarean sections simply because a woman would prefer one.¹⁰ Wiltshire CCG will not fund a caesarean section that is not based on clinical need unless an individual request has been approved.¹¹ Similarly, Greenwich, Lewisham and several other South East London CCGs will not fund caesarean sections in these cases unless they have already approved an individual application.¹²

The Royal College of Surgeons' survey of CCGs in July 2014¹³ found that there was significant inconsistency in the way that CCGs applied NICE and other guidelines, or that they had no policy for a number of high volume procedures. The absence of a clinical basis for restrictions, imposed periods of waiting and other rationing in a number of CCGs caused the Royal College of Surgeons concern.

Given CCGs' limited scope to ration, their decisions to limit services often cause disproportionate levels of controversy; precisely because they highlight the issue of the 'postcode lottery'. Northern, Eastern and Western Devon CCG's recent decision to backtrack on plans to limit access to surgery for severely obese patients and smokers, and to restrict the availability of second hearing aids and cataract operations in the face of public criticism, illustrates the limited room for manoeuvre that CCGs have when making decisions about how to spend their funds.¹⁴

THRESHOLDS IN HIP REPLACEMENT SURGERY FOR OSTEOARTHRITIS

NICE guidelines say that although it carries innate risks, hip replacement should be considered for cases where osteoarthritis is causing 'substantial' pain and impairment, and less extreme and costly measures such as weight loss programmes have been offered.

Yet many CCGs do not follow these principles, and apply their own, stricter limits on who can receive this treatment. Many break down different levels of pain and impairment, and provide the procedure only for the more serious. Many also stipulate that weight loss therapy or smoking cessation programmes must have actually been completed (though not necessarily successfully). Some, such as Mid Essex, use scored questionnaires to decide whether patients are eligible.

Cambridgeshire and Peterborough CCG will consider hip replacement only for 'uncontrolled, intense, persistent pain resulting in substantial impact on quality of life and moderate functional limitations which have failed a reasonable period of maximal conservative treatment'. This conservative treatment must include medication, physiotherapy, patient education, splints, weight loss and quitting smoking, if relevant.¹⁵

However, other CCGs such as Ipswich and East Suffolk apply similar, if less strict, criteria, and will not routinely provide hip replacements to morbidly obese people who do not lose weight.¹⁶

The Royal College of Surgeons recently found that, adjusting for age, the number of procedures per 100,000 people was 77.87 of the population in Newham CCG, compared with 360.31 in Kernow CCG.¹³

IS NICE WORKING AND COULD ITS ROLE BE EXTENDED?

CCGs are expected to comply with the recommendations of technology appraisals published by NICE, and to take note of its non-statutory guidance. NICE technology appraisals look in detail at the cost-effectiveness and clinical value of medicines, medical devices, diagnostic techniques, surgical procedures and health promotion activities, using clinical and economic evidence.¹⁷ The NHS is bound by a government directive to follow these NICE recommendations. However, the process is time consuming and relatively few treatments are assessed each year; in 2013/14, NICE published 32 technology appraisals.¹⁸ NICE's other guidance, such as its evidence-based guidelines and quality standards on different topics, is advisory and is treated by NHS England as not 'statutory guidance', which means it is given 'careful consideration' but may not be followed.¹⁹

NICE uses a quality-adjusted life year (QALY) in its technology appraisals.²⁰ One QALY is equal to one year of life in perfect health, so a treatment that extended a patient's life by a year, but with a lower quality of life, would be equal to an amount less than one QALY. The exact QALY value for a treatment is arrived at using clinical research and patient experience data.

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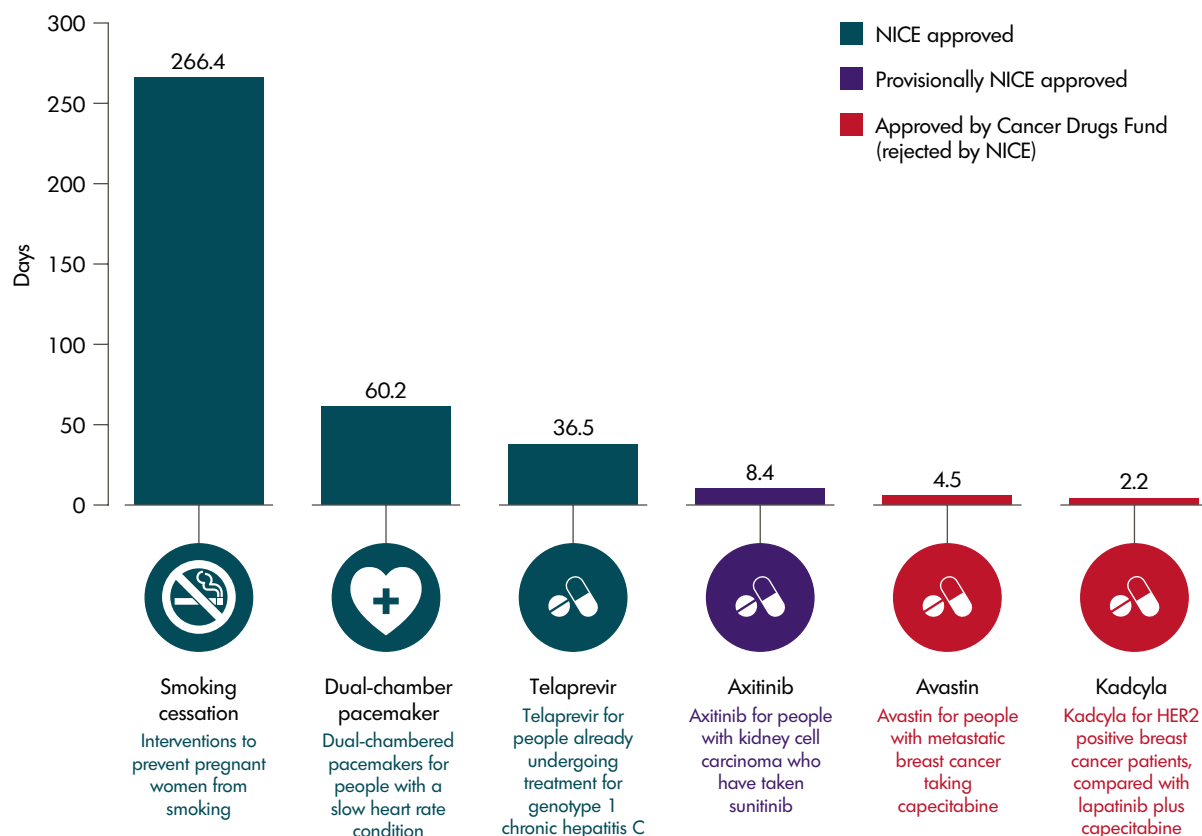
NICE's technology appraisal process comes at a cost, and it would not be feasible in terms of either expense or time taken to evaluate every product in use in the NHS. NICE therefore tends to target its assessments at drugs and procedures that are at the margin of cost-effectiveness; typically new products. Therefore, those that are very cheap and effective may never be assessed. As a treatment approaches a cost of £20,000 per QALY gained over existing best practice, NICE will scrutinise it closely. It will consider how robust the analysis relating to its cost- and clinical-effectiveness is, how innovative the treatment is, and other factors.²¹

As the cost rises above £30,000 per QALY, NICE states that 'an increasingly stronger case for supporting the technology as an effective use of NHS resources' is necessary.²² NICE has a more generous threshold for interventions at the end of people's lives, though there are mixed views about the degree of public support for this.^{23,24}

NICE's approach is internationally admired and copied, but there are some issues to consider:

- It would be tempting to mandate NICE's commissioning guidance in the same way as its technology appraisals. However, this would still not solve the problem of how to allocate resources between programmes – this would still need to be done locally as the sum of all NICE commissioning guidance for an area would almost certainly be unaffordable. NICE does not consider questions of allocative efficiency; that is the impact of its recommendations on other areas where there is no guidance to mandate specific treatment decisions.

FIGURE 2: ADDITIONAL DAYS OF QUALITY-ADJUSTED LIFE PER £1,000 FOR SELECTED INTERVENTIONS



Source: NICE technology appraisals 252, 263 and 324; NICE public health guidance 15; and guidance in development on 'Breast cancer (HER2 positive, unresectable) – trastuzumab emtansine (after trastuzumab & taxane)'.

- Even under the existing system, which mandates the funding of treatments approved by NICE technology appraisals, there is a very strong likelihood that these will be funded at the expense of other, less high profile treatments that may offer a better return in terms of QALYs. Reducing the variation in the availability of highly visible expensive medicines may result in increased variation elsewhere.
- It is still the case that the uptake of NICE technology appraisals is uneven. Research into prescribing activity during 2010/11 in England found that uptake of NICE-approved drugs for cardiovascular disease, diabetes and osteoporosis was higher than would be expected, but uptake of six drugs, one of which was trastuzumab for advanced breast cancer, was lower.²⁵
- NICE's ability to make decisions about the increasing number of very expensive new cancer drugs coming onto the market has been called into question, which has led to the creation of the Cancer Drugs Fund.

NICE is a success story: in many ways it has removed some hard decisions from politicians who often found themselves in a very difficult position. It has brought rigour to an often messy process in which multiple, highly variable decisions were made in different parts of the country.

WHAT IS THE VERDICT ON THE CANCER DRUGS FUND?

The Cancer Drugs Fund was established for England in 2011. Its budget has now risen from £200 million in 2013/14, to £340 million in 2015/16.²⁶ The fund pays for cancer drugs which would not otherwise be routinely available on the NHS. It is concerned with four groups of cancer drugs: those not yet evaluated by NICE; those deemed not to be cost-effective using the normal NICE evaluation criteria; those that are not going to be considered by NICE; and those that have not been prioritised through the NHS England prioritisation process. When first established, the fund considered the clinical benefits of drugs for patients, and did not take into account cost. Following a consultation process, NHS England announced in November 2014 that the Cancer Drugs Fund would begin to take the cost of drugs (as distinct from cost-effectiveness) into account, in addition to their clinical benefits.²⁷

'There is no clear rationale for separating cancer from other life-threatening conditions'

There is no clear rationale for separating cancer from other life-threatening conditions. The policy also has implications for the amount the NHS ends up paying for cancer drugs. Previously, a NICE appraisal might have resulted in a pharmaceutical company reducing the price of a drug in order to meet the NICE threshold. The existence of the fund weakens this incentive. There is also limited evidence that the public support the principles behind it.²⁸

The Cancer Drugs Fund is seen by many to be a fudge with a weak intellectual foundation which should be brought into a broader and more rigorous decision-making framework, such as that operated by NICE. The fund is not sustainable in its current form. Therefore, one option, which is favoured by the majority of respondents to the Nuffield Trust's latest survey of 100 health and social care leaders²⁹, is to hand back responsibility for evaluating these drugs to NICE. This could be on the basis of more generous assessment criteria, if there were public support for this, with interim recommendations for new treatments that have not yet undergone full cost-effectiveness appraisal.

HOW MUCH MONEY CAN RATIONING SAVE?

Rationing by restricting access to treatments is thought of as one way commissioners can balance budgets locally. There are two varieties of this:

- to exclude procedures that are thought to be of low value, such as breast enlargement or weight loss surgery
- to exclude patients on the grounds of lifestyle or some other factors.

In spite of stories in the media, there are not large numbers of tattoo removals, cosmetic breast operations or other ‘lifestyle’ treatments. In examining rationing policies for nine areas covering 15 CCGs, we found that no CCG was willing to fund breast augmentation, except for women with severe physical disfigurement following cancer surgery or a medical condition. None of the CCGs will fund tattoo removal unless people are having a serious allergic reaction, or have been forcibly tattooed, for example as part of human trafficking.

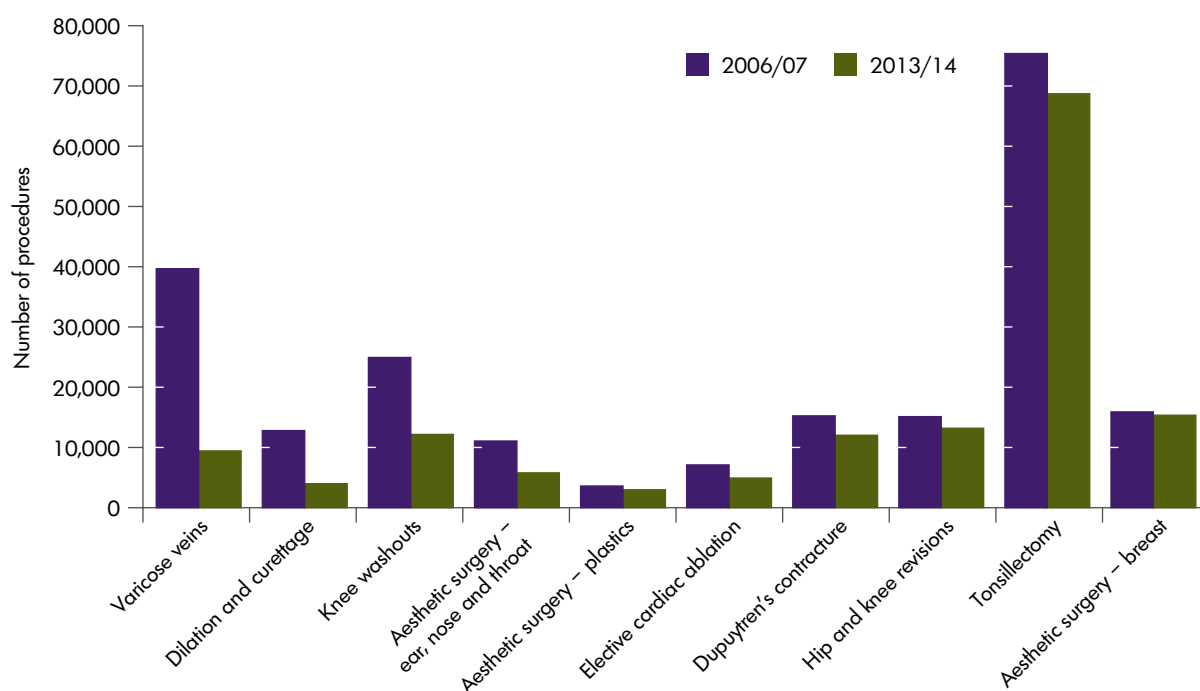
Seven out of the nine areas have an explicit rule that cosmetic surgery will not be routinely funded across the board. The only two that do not, Mid Essex and the Canterbury and Coastal area, state similar policies individually for each common cosmetic procedure. Cumbria CCG’s policy is typical in stating: ‘Surgery for primarily cosmetic reasons is not eligible for NHS funding. A significant degree of exceptionality must be demonstrated before funding can be considered outside of these policies. Specifically, psychological factors are not routinely taken into consideration in determining NHS funding.’³⁰

With regard to caesarean sections, it is not clear how many women are electing to have caesarean sections for non-medical reasons. However, the numbers involved appear to be small.³¹ And weight loss surgery has in fact been shown to be relatively cost-effective.³²

Work for Monitor has suggested that the amount that could be saved by avoiding the use of elective procedures and drugs of little clinical value is £0.9 billion to £1.8 billion.³³ There are two points to note here. First, these are procedures of *low* value – not *no* value. This means that some patients could benefit from them, meaning the actual amount saved is likely to be lower and creating a need for further approval or monitoring processes.

It has been hoped that patient recorded outcome measures could be used to identify procedures where patients get low levels of benefit and that these could then be limited. The data do not lend themselves to this and it is not easy to identify for individual patients whether they will benefit or not, in advance of the treatment.³⁴

FIGURE 3: DECREASING ACTIVITY IN PROCEDURES JUDGED TO BE OF LOW CLINICAL VALUE, ENGLAND 2006/07 – 2013/14



Source: Health and Social Care Information Centre. Hospital Episode Statistics. 2006/07–2013/14.

In the second category of rationing – restricting access based on other factors – there are some clinical reasons for asking patients to stop smoking or to lose weight before operations, but there is disquiet about this where it just looks like a way of saving money (as happened with the recent example of Northern, Eastern and Western Devon CCG¹⁴). Attempts to use these clinical criteria as a mechanism for making savings have generally proved problematic. There is a more significant question over whether to do so is legitimate, and whether the relatively small savings are worth the trouble.

KEY MESSAGES FOR POLICY-MAKERS

Rationing is taking place whether we like it or not – the question is the degree of transparency surrounding approaches used to ration care. There is a fixed budget and a need to prioritise funding, and many of the proposals often put forward for solving this (for example no longer funding tattoo removal) are red herrings. There is no method that removes judgement and, however carefully methods and rules are put in place, decisions will always be challenged, particularly when difficult individual cases arise.

At the moment we have a pragmatic approach of muddling through, bolstered by some reasonable methodology. It is not clear that there is a much better answer in other systems or in the policy literature. However, **there is scope to improve the level of transparency in the system, particularly at the level of local commissioners; to use public consultation more effectively and consistently; and to communicate better the dilemmas faced by decision-makers.** That said, it is not clear that the general public are very interested in being closely involved in these decisions,³⁵ although it will help to increase the accountability of the system. We believe that greater transparency and more explicit priority-setting processes are preferable to an implicit approach largely hidden from public view.

A careful balance needs to be struck between ensuring consistency at a national level over what drugs and treatments are funded, and how much autonomy over local decision-making is afforded to CCGs in order to tailor services for their local communities. **There is a need to be clear about what the rules are: what it is permissible for a CCG to do in varying what is offered; what they have to demonstrate in terms of public involvement and the rational basis of their decision; and what national leaders consider to be ‘acceptable variation’.**

There is a tension between the role of politicians at the national level in helping to shape the landscape within which rationing decisions are taken and their duty to speak up for their local constituents.

Intervening in individual commissioning decisions can be particularly problematic if it undermines the legitimacy of the decision-making process that successive governments have put in place.

In our 2012 report, *Rationing Health Care: Is it time to set out more clearly what is funded by the NHS?*,⁴ **we recommended that a set of principles should be established to shape how public money is spent in the NHS, and to inform decisions about what should no longer be paid for.**

We also proposed that decision-making in CCGs should be made more transparent, so that departures from certain national guidelines, and from NHS commissioning principles, are subject to proper scrutiny before they are finalised. Both of these steps would be beneficial in moving towards a

position where commissioners are better able to justify decisions about how best to use scarce resources.

NICE's approach to appraising new technologies is internationally admired. But the NHS is only required by government to adhere to some of NICE's recommendations. **Making it compulsory to follow all NICE guidance would not solve the problem of how to allocate resources between programmes, as providing everything the guidance requires for an area would almost certainly be unaffordable.**

To date, the rationing process has been one of muddling through, with some approaches based on more transparent principles at the margins.

As financial pressures increase, the legitimacy of some approaches, such as restricting access to surgery for financial reasons, using clinical criteria, and the Cancer Drugs Fund, will face greater scrutiny.

Finally, **given the lack of evidence to justify the existence of the Cancer Drugs Fund**, and the challenges to the wider system posed by the fund, we believe, given the expertise of NICE in analysing the cost-effectiveness of all drugs and treatments, **NICE should resume responsibility for making decisions about the availability of these drugs.**

This is the second in a series of policy briefings on the challenges facing the health and social care system. Read the first one – *Is general practice in crisis?* – at: www.nuffieldtrust.org.uk/publications/general-practice-crisis

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