

A National Health Service for Patients

Anton Howes

With tight budgetary constraints and scarce resources, rationing of healthcare takes place at all levels of the National Health Service. However, these inevitable rationing decisions are taken by clinicians, politicians and bureaucrats, but with no direct say from patients or the public. Those who both fund the system, and stand to gain or lose the most from the way it works, therefore have no powers to hold it directly accountable. The potentially disastrous effects of this crisis of accountability have been exposed by recent scandals over poor quality care, most notably that at Mid Staffordshire. This paper proposes that Patient-led Commissioning Groups (PCGs) be allowed to set up alongside existing Clinical Commissioning Groups, in order to establish the accountability of the NHS to patients and the public. The creation of PCGs would lead to improvements in access to primary care, more joined-up care for patients, and may result in pressure to keep healthcare costs low through decentralised pay bargaining. The reform would build upon existing institutions, being achieved incrementally and without top-down upheaval. A patient-led service is the only way to ensure that it puts patients first, going beyond the rhetoric so that the public can truly own their NHS.

The NHS suffers a crisis of accountability. The gross negligence that has come to light at Mid Staffordshire is an extreme example of the current system's failings, but the entire service is susceptible to similar abuses because of a lack of direct accountability to patients. The Health and Social Care Act 2012 put some control of the NHS into the hands of General Practitioners (GPs) and other clinicians, but does little to give patients and the public a real say in how their service is run.

The service is committed to providing a comprehensive, universal and high standard of care, free at the point of delivery. However, with scarce

resources, and wide demands, politicians, managers and clinicians make numerous decisions about how to ration care. These decisions are undertaken without direct accountability to the public, and without patients – those whose lives and health as individuals are most affected – having a say over them.

■ **Problems: A Crisis of Accountability**

Rationing of NHS services takes place throughout the system. First, the Treasury allocates budgets to the Department of Health, against competition from

education, welfare, defence, and other spending commitments made by central government. This amount immediately imposes limits upon what the NHS can and cannot afford to do.

Second, the Department of Health designs formulas, based on past experience, as to the amounts Clinical Commissioning Groups (CCGs) will have available to spend on their patients' behalves. Clinical Commissioning Groups are GP-led consortia, also involving other clinicians such as doctors and nurses. Within the 'internal market' of the NHS, CCGs are the buyers of healthcare, directing funds to providers of their choosing. On 1st April 2013 they replaced Primary Care Trusts (PCTs), manager-led bodies that tried to have an input from GPs, clinicians, local authorities and others.

One significant outcome of the abolition of PCTs is that another body must commission primary care (i.e. GP's appointments). If CCGs were to do this, then they would face a conflict of interests, themselves being GP-led consortia. Therefore, NHS England (formerly known as the NHS Commissioning Board or NHS CB), a centralised national body, now undertakes this role. The obvious problem with this model is that it has massively centralised the commissioning of primary care, making it even more difficult for patients to have an input on the services they receive from GPs. NHS England itself has admitted 'it will be a significant challenge to move from many different systems to a national operating model, while retaining vital local responsiveness and sensitivity'.¹

Based on the experiences of CCGs' pre-2013 predecessors, PCTs, there are a number of different strategies by which commissioners' funds can be allocated. At the two extremes, some of these strategies are more catered to utilitarian views, emphasising cost-effectiveness at the expense of individual patients, while others can be more centred on patients as individuals. There are of course many other options in between, while other strategies take into account criteria like national targets and health inequalities.² One further risk with the centralised, national-level commissioning decisions of NHS England is that they will tend to favour more utilitarian approaches, potentially allowing them to ignore individual patients' needs. NHS England has created a series of Local

Professional Networks (LPNs) in an attempt to mitigate this effect, allowing input from local clinicians. However, it is unclear how effective these will be, and they still focus on allowing clinical rather than public input, so there is still no direct route for patients and the public to have an effect on the commissioning of primary care.

The purchasing strategies of commissioning groups, whether CCGs or NHS England, are therefore highly dependent on the values of those in charge: namely GPs, other clinicians and managers. However, their choice of strategy can have a large impact on patients. Without being

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able to distribute resources by price, commissioning groups ration care through a number of non-monetary means. For example, by slowing down treatment rates and increasing waiting times, CCGs can limit care by delaying it, often deterring people by forcing them to drop out of excessively long queues. In a less visible manner, CCGs can also introduce eligibility thresholds, for example requiring a certain level or frequency of health complaint

before patients can be referred to treatment. They can also divert demand to social services, placing burdens on local authorities and budgets that they do not directly control. In terms of the contracts they negotiate with providers, CCGs can also cap the number of treatments they are willing to commission from a particular hospital.³

While CCGs focus on commissioning secondary care, NHS England will have to make decisions about how to allocate primary care too. The centralised nature of primary care commissioning is likely to result in even more rationing at the expense of patient needs. For example, under the 2004 contract, both nationally agreed and locally agreed GP contracts give them an optional exemption from out-of-hours services, which has been taken up by 90% of General Practitioners. This means that NHS England has to limit the availability of out-of-hours primary care, resulting in the vast majority of the public being forced to take time off work simply in order to get a GP appointment. The current Secretary of State for Health, Jeremy Hunt MP, believes that this rationing of primary care in favour of GPs' terms has resulted in excessive strain being placed on Accident & Emergency (A&E) services.⁴

The centralised negotiation of GPs' wages is nothing new – indeed, it dates back to the introduction of National Insurance for working

men between the ages of 16 and 65 in 1911. This pre-NHS system used member-run Approved Societies to commission primary care, building on the pre-1911 network of membership-led mutuals and friendly societies. The 1911 reforms took the negotiation of GP contracts out of the hands of multiple friendly societies (essentially, consumer cooperatives), and put it into the hands of the state. The pre-1911 combinations of patients had forced a large number of clinicians to compete on quality, service and price for a contract to treat multiple patients, rather than being able to choose between many more individual patients.⁵

The decentralised system had thus been able to keep GPs' remuneration relatively low, while also offering night visits and same-day service when private doctors' associations did not. However, when national pay bargaining was introduced in 1911, per capita rates of remuneration for doctors rapidly increased from an average of fewer than 5 shillings per patient to 7s in 1912, and then to 11s in 1920. In 1924, the medical profession was able conditionally to resign *en masse*, pressuring the government into stopping planned wage cuts, and by 1938, capitation rates were at 11s 2 pence.⁶ The national pay bargaining of the NHS was thus a continuation of this trend, with negotiation occurring through joint management and trade union councils, and with no place for local bargaining or managers' discretion. Like in 1924, the breakdown of negotiations had national consequences, putting clinicians in an extremely strong position to threaten industrial action in the 1970s too.⁷ In the historical context of national and centralised contract negotiation for the medical profession, the generous provisions of the 2004 contract for GPs are unsurprising, but any attempt to renegotiate the contract by the Secretary of State for Health will face hugely strong political opposition.

The strong bargaining position of the medical profession can have negative impacts on patient care. In the context of rationing, the money to pay higher wages must result in less money reaching patient care. For example, in 1987, the NHS faced a financial crisis, partly due to doctors and nurses being awarded a substantial pay rise. This move meant that the budgets for beds and services had to be cut, as the overall NHS budget did not expand enough to accommodate the increase.⁸ Similarly, a reduction in the demands on clinicians for services must result in greater rationing of services available

to the public. The 2004 contract for GPs is an excellent illustration of this, drastically reducing out-of-hours access to primary care, and if the Health Secretary is to be believed, resulting in excessive strains on A&E services. Due to the overly centralised nature of pay bargaining for GPs and other clinicians, rationing decisions of these kinds can take place at the expense of patients, but with no public input or accountability.

Rationing of the kind outlined here is inevitable

The strong bargaining position of the medical profession can have negative impacts on patient care

in the context of scarcity and free provision at the point of use, but given the vast array of strategies that CCGs and NHS England can use, and the subjectivity of the values that inform those strategies, it is surprising that patients and the public have no direct way in which to influence CCGs' decisions. In the current model, the family doctor is infallible, but it is the public who both pay for the system as taxpayers and are most

affected by its consequences as vulnerable patients.

However, CCGs are also constrained by the recommendations of the National Institute for Health and Care Excellence (NICE) as to which treatments and drugs are cost-effective. This process straightforwardly denies specific forms of intervention, limiting the available treatments that patients are entitled to receive from the NHS. The way NICE reaches its conclusions is debatable – for example, the thresholds used to calculate the cost-effectiveness of treatments are completely arbitrary and have not been updated to take inflation into account since the foundation of NICE's original form in 1999. Furthermore, the measures used (Quality Adjusted Life Years) discriminate against the disabled and against treatments to extend life by another few weeks or months.

After lengthy and widespread campaigning by patients, there is now a separate fund for cancer drugs to help solve the latter problem, although in the context of scarce resources, the cost of these drugs may crowd out the use of others.⁹ Nevertheless, this solution is not a systemic one – it was politically popular to respond to cancer patients' lobbying, but the same cannot be said for all groups discriminated against by this denial of treatment. Patients still have no direct way in which to influence the decisions about what kinds of treatments are available or recommended to the NHS as a whole.

It is still not clear whether or not the Health and Social Care Act 2012 allows CCGs to treat NICE recommendations as mere guidelines or imposed limits on the care they may purchase. The former is certainly preferable in the interests of sensitivity to local conditions and individualised patient needs. Nevertheless, even if CCGs are not forced to deny specific treatments based on NICE's recommendations, CCGs will still have to determine which treatments they will and will not purchase on patients' behalf. In the absence of alternative advisory bodies to NICE, it is likely that NICE's advice on which treatments to commission will still be followed. CCGs can develop their own 'exclusion lists' too, refusing to commission particular treatments for their patients, whether or not they have been recommended by NICE. For example, some PCTs simply did not offer any funding for treatments they judged to be of lower clinical value, such as IVE, surgery for lower back pain, hysterectomies for heavy menstrual bleeding and grommet insertion to treat glue ear.¹⁰

Some treatments have also simply been considered too costly for the NHS and have been directly restricted from the political centre. From as early as 1949, merely a year after the NHS's foundation, levies on prescriptions were introduced, with charges for spectacles and dental treatment following in the early 1950s. This trend has continued throughout the NHS's history, with eligibility for NHS spectacles and eye testing further reduced in 1985 and 1989 respectively.¹¹ In all of these cases, whether the decision has been taken by NICE, CCGs or the political centre, the direct denial of patient entitlements takes place based on the decisions of panels of medical experts, clinicians and politicians, but with minimal input from patients themselves. Even more crucially, CCGs' exclusions of different treatments result in unequal entitlement to treatment across the country. This goes directly against the NHS mantra of comprehensive care, while giving patients no say in how treatment is distributed, nor the ability to directly hold decision-makers accountable.

The role of NICE also highlights the way the NHS can introduce newer and more expensive treatments into the system, initially only rolling

them out to specialist centres until they fall in price enough to 'universalise the best'.¹² This process at least in the short term accentuates the inequality of treatment across the country, being available to patients who by good fortune live close to specialist centres, but excluding those who do not. Further inequalities arise from the configuration of NHS services. Patients and the public have no way of insisting on where specialist centres or even A&E departments are located. They are also almost powerless to prevent their relocation or

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axing. Instead, these decisions are left to providers themselves, the influences of CCGs, NHS England and politicians within the Department of Health. Taking a national view, these bureaucratic bodies can easily reconfigure or close services in particular areas, without having to answer to local protests, even in the rare cases when protesters can organise themselves effectively.

Providers also decide how best to allocate limited time and resources to individual patients. Managers of NHS Foundation Trusts and other providers have to take decisions about how to ration care, and clinicians

themselves often engage in 'bedside rationing'.

Managers have a number of rationing tactics at their disposal. They can close wards, reduce the number of beds on wards, reduce services on offer and reduce patients' length of stay. They can also reconfigure services between hospitals controlled by a particular trust, for example by centralising services to larger hospitals, thereby raising patients' travel costs to access them.¹³ The effects of rationing can be very visible, manifesting themselves as long waiting times.¹⁴

Clinicians also engage in rationing, although it is often more implicit or internalised. For example, more than minimal care is sometimes denied based on individual doctors' judgements in cases where there is little chance of recovery, particularly to young children or the elderly with serious conditions. Relative to other developed countries, many British doctors focus predominantly on increasing life expectancy, sometimes at the expense of responding to complaints about pain.¹⁵ When surveyed, doctors also report taking rationing decisions using criteria that the public may not normally find acceptable, such as a patient's ability to exercise pressure or their contributions to society.¹⁶ Both of these criteria go against the NHS's principles of providing universal and comprehensive

treatment, but patients are powerless to insist that NHS values and their own values are upheld.

Although rationing of some kind is inevitable, providers do not face the same sort of transparency that CCGs and NHS England must face.

Nevertheless, even without the same transparency, commissioning groups are able to hold providers to account. They are potentially able to withdraw funds until providers can guarantee the expected standards of care, and in certain cases may be able to end contracts when they feel that providers fail patient needs. Unfortunately, the House of Commons Health Committee noted in 2010 that in practice commissioners (PCTs at the time) 'continue to be passive, when to do their work efficiently they must insist on quality and challenge the inefficiencies of providers', though the effectiveness of the new CCGs still remains to be seen.¹⁷ Nevertheless, despite the potential benefits from holding providers to account, patients and the public are unable to do this directly, instead relying on clinicians and managers to do this without direct accountability, but on their behalf through CCGs.

Rationing is inevitable in the context of scarce resources. But this is no excuse for a lack of accountability throughout the NHS to patients and the public, the people who both fund the system and stand to gain or lose the most from the way it works. The disastrous care provided at Mid Staffordshire serves as a reminder of just how badly an unaccountable system can fail those who depend so much on it for their health, wellbeing and lives. As this section has outlined, patients and the public are shut out of decisions made at the political centre by the Ministry of Health, NHS England and NICE, despite the huge ramifications of those decisions regarding the types of treatment they are entitled to receive, the availability of treatments and the quality of treatment. Similarly, they have no control over the GP-led Clinical Commissioning Groups that choose and ration their secondary care, nor the power to use them to influence the decisions of health providers.

Solutions: putting patients back in control

While patients and the public have not had direct involvement in decisions about the commissioning and rationing of their own healthcare, there

have been numerous government initiatives to provide a voice for patients and the public. These initiatives have been founded and refounded over the decades, each as unmemorable as the last: Community Health Councils, then Patient and Public Involvement Forums, then Local Involvement Networks, and now HealthWatch.¹⁸ All of these initiatives have been top-down

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organisations, with their parameters, management and activities set by politicians, and with no real powers to force the health system to comply with the public's demands. Local HealthWatch groups act as mere directories for services, collecting and collating patient experiences and passing them onto the national body. At the very most, providers and commissioning groups are bound by law simply to listen and reply to what the national HealthWatch has to say.¹⁹ HealthWatch and its predecessors are ineffectual if patients and the public

wish to determine the way their health service is run. They can therefore be forgiven for failing to notice or use them.

Individuals already have a choice of commissioning groups; they can choose to stay with the GP of a particular CCG, or register with a new GP in a different CCG. This report proposes that individuals also be allowed to register directly with non-clinical commissioning groups, which would be able to commission GP services, other primary care services and hospital services too. This measure would allow patients and the public to form their own commissioning groups, or directly empower others to do this on their behalf, negotiating contracts with both primary and secondary providers. Rather than simply caring for a passive public caught within the catchment areas of a few GP practices, patient-led groups would cultivate an active membership, able to be directly involved in decisions and hold the group's management's decisions to account.

Allowing and encouraging the foundation of 'lay' (non-clinician) commissioning groups would allow patients and the public to impose their own demands on GP services. For example, a commissioning group made up of workers in a particular industry may commission work-friendly and night-time opening hours. Alternatively, a rural group in an area with bad transport links may

demand and commission GP home visits rather than having to travel themselves to distant practices. These proposed Patient-led Commissioning Groups (PCGs) would also be able to commission secondary care, for example working with the GPs they have on contract to ensure that their members receive joined-up care throughout their NHS experience, with effective communication between all clinicians involved. The idea is similar to that for the conversion of PCTs to consumer mutuals proposed by the Civitas Health Policy Consensus Group in 2003, which was made up of prominent senior NHS consultants and policymakers from across the political spectrum.²⁰ In practice, the proposed PCGs would also be consumer mutuals, but without the need to force existing commissioning structures to adopt that form.

Patient-led Commissioning Groups should also be able to experiment with different governance structures. By having a variety of different structures operating within the NHS, patients would be able to select the models that best fit their health needs and which allow them the greatest control over the services commissioned on their behalf. Given the need for members of the public purposefully to re-register with the proposed PCGs, the PCGs would have to make an extra effort to appeal to members of the public on both the quality of service and on the effectiveness with which they can allow patients to have an impact on decisions about their own care. This opt-in system is crucial to ensuring that any new PCGs are both effective and responsive to their members – otherwise they will fail to keep members.

By commissioning both primary and secondary care, PCGs would allow patients to have a direct impact on decisions that would otherwise be taken by managers and politicians in NHS England, or by clinicians and managers in CCGs. This would mean a significant decentralisation of power from the political centre. Provided NICE recommendations are treated as guidelines rather than restrictions, PCGs would allow patients to have a direct say over which treatments are rationed and which are not. This would, for example, allow patients to insist that new treatments really are rolled out comprehensively, in keeping with the NHS's founding principles, rather than leaving some areas behind.

Trade unions and other large non-profit mutuals like friendly societies and cooperatives should be encouraged to set up PCGs

This decentralisation of power and accountability also provides an opportunity for GP contracts to be renegotiated at a local level. If PCGs were fully empowered to negotiate their own contracts with primary providers, they would be able to negotiate their own pay scales and the services that they expect from GPs. This would mean a return to a situation only seen before 1911, when numerous friendly societies were able to keep wages at a reasonable level, while securing the most open access for their members to health services. It

would also avoid a large political fight between the Secretary of State for Health and GPs, while giving patients and the public a say in whether resources should be allocated to paying higher wages and better terms for GPs or towards patient care.

The creation of PCGs should be as open as possible to encourage a number of alternatives for patients. In theory, there could be as many different PCGs as there are visions of how rationing should occur, but

in practice, the success of PCGs will rely on their ability to attract and retain members. Due to the recent abolition of PCTs, there are many managers recently made unemployed by the NHS with experience of commissioning who could carry out functions on behalf of PCG members. However, unlike the old system where managers were appointed in a way that was unaccountable to the patients affected, PCG members would be able to empower their PCG to hire and fire managers on their behalf, keeping managerial rationing decisions directly accountable to the demands of patients and the public.

There are also numerous existing member-based organisations that could be first-movers in setting up PCGs. For example, trade unions and other large non-profit mutuals like friendly societies and cooperatives should be encouraged to set up PCGs. They already possess organisational infrastructure, governance structures that to varying degrees involve their members and large membership bases that they could call upon to register with their associated PCG. Indeed, trade unions and friendly societies in particular would be able to rebuild the legacy they had of purchasing healthcare for their members long before either National Insurance or the NHS were introduced. However, they would be able to operate within the NHS rather than outside of it.

PCGs would have a large potential to remould the NHS to cater to patient demands. For example, if

the members of a particular PCG have an ideological bias against for-profit providers, they would be able to act upon that preference, only commissioning from public or non-profit providers. They would be able to do the same when making decisions about the quality of treatment, refusing to commission the treatments of any particular provider until they comply with patients' expected standards of care. Similarly, if for example a particular NHS Foundation Trust planned to cut a particular ward or department or hospital, a local campaigner or politician could set up a PCG to act on behalf of affected locals who feel strongly about preventing any closures, using their commissioning powers to keep provider services as they are. NHS providers must supply whatever is demanded in order to stay open. By putting patients and the public in control of the demand side of the NHS's internal market, they can have a huge influence on the NHS's provision of healthcare too.

Patient-led Commissioning Groups also present a way for social care to be integrated into the system, resulting in a more joined-up approach to health and social care by the state. Personal budgets, either as council-managed funding allocations or as direct payments, allow those eligible to receive them to commission healthcare as individuals, or have their local authority do so for them. This system has been rolled out in England since 2008 and could be closely integrated with PCGs, for example with individuals entrusting their direct payments to the group as members, to have them commission both their social care and health needs in a joined-up manner. Alternatively, individuals could request that councils transfer their personal budgets to PCGs, de facto becoming members.

In addition to providing a greater say for the public, the introduction of PCGs may also help retain the public's significant trust in clinicians. One key complaint about the introduction of CCGs was that it would force GPs to make more rationing decisions, which could lead to a public perception that GPs were making decisions on the basis of cost-effectiveness rather than in the best interests of individual patients.²¹ It is still too early to see if this fear is justified, but PCGs offer a way out nonetheless – members of the public could have a direct impact on decisions, and PCG managers would be held directly accountable for decisions made on their members' behalves. Clinicians would purely be providers rather than both commissioners

and providers, ridding the system of any potential conflicts of interest and allowing clinicians to focus exclusively on individual patient needs.

In conclusion, allowing and encouraging patient-led commissioning groups would allow patients and the public to have direct control over the decisions that are made in their name. As the funders and beneficiaries of care, it is right that care should

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be directly accountable to patients, rather than only to politicians, managers and clinicians. This is the only way to ensure that the NHS becomes an organisation that puts patients first. The proposed PCG model provides opportunities for fully joined-up care, with PCGs able to secure and commission primary, secondary and social care for their members. It also lifts a burden from clinicians who worry about being forced to make rationing decisions

at the expense of the individual needs of their patients, and which could result in conflicts of interest and growing distrust for clinicians.

Most importantly, the proposed PCG model can be achieved incrementally and without any top-down upheaval, complementing and running alongside CCGs and NHS England, and potentially using former PCT staff with experience of commissioning. It will also be able to incorporate both individuals with personalised care budgets and large-scale membership groups with organisational experience that could be applied to providing the best and most comprehensive care for patient-members. Indeed, the bottom-up nature of the reform is important in ensuring that PCGs properly reflect members' demands – the onus should always be on them to attract and retain their members. The PCG model would finally allow the NHS the dynamism and flexibility to reflect and respond to the individual needs of the patients it serves.

■ Glossary

A&E	Accident & Emergency
CCGs	Clinical Commissioning Groups
GPs	General Practitioners
LPNs	Local Professional Networks
NHS CB	NHS Commissioning Board (now known as NHS England)
NICE	National Institute for Health and Care Excellence
PCTs	Primary Care Trusts
PCGs	the proposed Patient-led Commissioning Groups

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- 5 Green, *Working Class Patients and the Medical Establishment*, 116-8.
- 6 'Proceedings of the RCNHI,' 403-5; 'Supplement 1776', 357-62; Political and Economic Planning, *Report on the British Health Services*, 133.
- 7 Edwards, *The National Health Service: A Manager's Tale 1946-1992*, 11.
- 8 *Ibid.*, 133-4.
- 9 Klein, *Thinking About Rationing*, 10-13.
- 10 *Ibid.*, 22.
- 11 Edwards, *The National Health Service: A Manager's Tale 1946-1992*, 96.
- 12 Timmins, *The Five Giants*, 131-2.
- 13 Klein, *Thinking About Rationing*, 30-31.
- 14 *Ibid.*, 1.
- 15 Evans, *Sixty Years On*, 35.
- 16 Klein, *Thinking About Rationing*, 33-4.
- 17 Health Committee, 'Commissioning: Fourth Report of Session 2009-10 Volume I.'
- 18 Klein, *Thinking About Rationing*, 41.
- 19 'Www.healthwatch.co.uk FAQs'
- 20 'A New Consensus for NHS Reform.'
- 21 Klein, *Thinking About Rationing*, 43.



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Notes

- 1 NHS Commissioning Board, 'Securing Excellence in Commissioning Primary Care,' 26.
- 2 Klein, *Thinking About Rationing*, 13-14.
- 3 *Ibid.*, 15-24.
- 4 'Hansard 21 May 2013,' col. 1055-6.

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