Rationing in the NHS: the views of health and social care leaders

Health and Social Care Leaders' Panel

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Survey no. 3, February 2015

In the run-up to the 2015 General Election, the Nuffield Trust is 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.

This is the third survey, drawing on the views of panel members from across the NHS and social care, including hospitals, ambulance trusts, community services, general practice, local authorities, and private and voluntary sector providers. The patients' perspective is provided by individuals working in local Healthwatch bodies. The first survey was conducted in June 2014, the second in September 2014 and this third one in December 2014.

Each survey asks the panellists a number of 'tracker' questions on overall perceptions about the quality and sustainability of NHS services. In addition, each survey focuses on a specific topical issue. This third survey looks at rationing in the NHS, exploring the challenges inherent in rationing policy. These results will provide useful insights for policy-makers into the views of health and social care leaders as we approach the 2015 General Election.

We encourage you to comment on our survey findings and find out more about the Health and Social Care Leaders' Panel. You can:



follow the project on Twitter via #HealthLeaders - tell us your views



find out more about the 100 health and social care professionals who have come together to form our panel: www.nuffieldtrust.org.uk/health-leaders-panel



read analysis and commentary on the survey findings from panel members and Nuffield Trust experts via our blog: www.nuffieldtrust.org.uk/category/tags/general-election-2015



be the first to receive our latest reports, analysis and invitations to events by signing up to our monthly newsletter and email updates via: www.nuffieldtrust.org.uk/newsletter

Key points

- **68**% of our panellists think that people should get the same package of NHS services no matter where they live.
- **But over half** think commissioners should be able to tailor decisions to local circumstances, even if this results in variation.
- **48%** think that budget considerations should not limit the services provided by the NHS.
- But **53**% disagree with the idea that the NHS should *not* limit access to services.
- **Financial pressures** are seen as the biggest restrictor of clinically effective care.
- 14% say that obsolete or ineffective procedures are still taking place in their area.
- **Seven in ten** panellists say that the Cancer Drugs Fund should be wound up. Of those, the majority felt that responsibility should be given to the National Institute for Health and Care Excellence.
- 31% of our panellists consider that quality of NHS care for patients has worsened over the last year.
- 58% believe that the NHS will be free at the point of use in 10 years' time.
- Three in ten panellists identified access to urgent care services as the
 most concerning access challenge. The same proportion identified access
 to social care for vulnerable people as most concerning.
- **More than three quarters** of panellists think that the quality of social care services has worsened over the last year.

Introduction

One hundred leaders drawn from across the NHS and social care system have come together to form the Nuffield Trust's Health and Social Care Leaders' Panel. The majority of our 100 panellists work in acute and mental health trusts, ambulance trusts, community services, clinical commissioning groups (CCGs), local authority social services departments, and private and voluntary sector providers. Fifteen of our panel are GPs. The patient's perspective is provided by individuals working in local Healthwatch bodies. Find out more about our panel members.

Methods

Our third poll was conducted between 24 November and 19 December 2014, via an online survey. In addition, a small number of responses were received in early January 2015 due to personnel changes among the panel.

In total, 80 of our 100 panellists responded. Of the 80 respondents, 35 are senior NHS managers, 25 are clinicians or clinical leaders, 12 are from local Healthwatch bodies and eight are from the social care sector. Of the health service managers and clinicians, 26 are from acute hospitals; 13 are from CCGs; six are from NHS community trusts; five are from acute mental health providers; five are from NHS ambulance trusts; and five are from private or voluntary sector providers.

The panel members are named on our website but their individual responses to the survey are anonymised.

This survey is accompanied by a separate policy briefing, <u>Rationing in the NHS</u>, which explores in more detail some of the issues and themes raised in the survey. This briefing is the second in a series on the issues and challenges facing the political parties in the run-up to the General Election.

Find out more about our General Election work at: www.nuffieldtrust.org.uk/general-election-2015

Findings and analysis

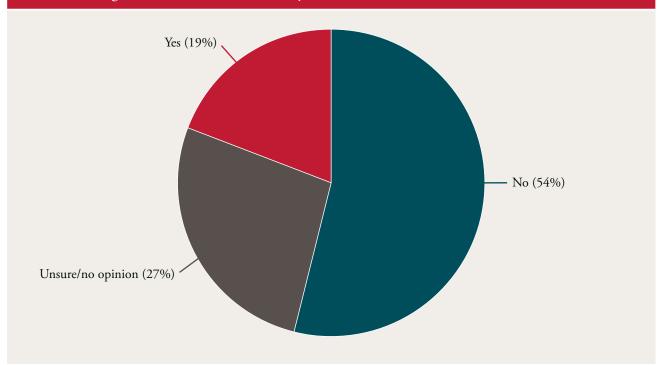
Are you aware of any clinically effective procedures/medications/devices available in the NHS elsewhere in England that are not available in your area?

Fewer than one in five respondents (19%) said they are aware of clinically effective interventions that are not available in their area (see Figure 1), suggesting that if rationing of effective services is taking place, it is having a limited impact at present. However, respondents identified some important services that are unavailable locally, including:

- mental health crisis teams
- National Institute for Health and Care Excellence (NICE)-approved psychological therapies
- specialised bariatric surgery
- more than two cycles of IVF
- specialist eating disorder services.

In some cases, for example specialist rectal surgery, provision has been centralised, but it is unclear from responses to the survey whether this is for clinical or cost reasons.

Figure 1: Are you aware of any clinically effective procedures/medications/devices available in the NHS elsewhere in England that are not available in your area?



Are you aware of any obsolete or clinically ineffective procedures that are still being carried out routinely in your area?

Although a majority of respondents (61%) said they are not aware of obsolete or clinically ineffective procedures still occurring routinely in their area, 14% of panel members did report that obsolete and ineffective procedures are still taking place. Examples include:

- tonsillectomies
- grommets
- knee wash-outs
- homeopathy
- cosmetic procedures such as pinning back ears, and breast enlargements and reductions that have been funded via individual funding requests.

Which factors do you think, at present, have the greatest impact on restricting access to clinically effective procedures/medications/devices?

The financial pressures facing the NHS are seen by respondents as having the greatest impact on restricting access to clinically effective care; 30 out of 79 rated financial pressures as the most significant. Providers undertaking their own priority setting is viewed as having the least impact, with 38 out of 79 respondents ranking this last. This could be because, at present, payment systems tend to reward providers for undertaking additional activity, rather than for remaining within a budget, which might weaken the incentives for providers to ration.

To what extent do you agree/disagree with the following statement: 'The NHS should limit access to health services in order to remain within the budget allocated to it by the government'?

Views about this question are mixed, with 48% of respondents either disagreeing or strongly disagreeing, and 37% agreeing or strongly agreeing. The additional comments provided by respondents illustrate the difficulty of the challenge. Several argue for provision to be based on need; others emphasise the role of priority setting to control expenditure. One respondent said:



We have a duty to redesign delivery, but no right to restrict access to necessary care

Community trust panel member

Another said:



Given that demand is increasing for a number of reasons, there are only three options: increase funding; reduce access; or go bankrupt

CCG panel member

Respondents are keenly aware of the difficulty of making these decisions. One commented:



Whilst the reality is the limit to the budget, [it] needs [the] judgement of Solomon to decide where the funding should be targeted and where the cuts should be made. So many emotional elements to the decisions

Healthwatch panel member

Another characterised the dilemma as follows:



Rationing is and has always been a necessary approach when resources are cash limited and demand is growing and potentially infinite; what matters is whether it is rational, fair and explicit, or hidden and thus potentially irrational or unfair

CCG panel member

To what extent do you agree/disagree with the following statement: 'The NHS should not limit access to services – funding should be made available by the government to meet the cost of services that clinicians decide should be provided'?

When the question was reversed, 33% of respondents said they agree or strongly agree that the NHS should not limit access to services, while 53% said they disagree. The lack of consensus revealed in the panel's answers to these two questions illustrates the scale of the challenge faced by those who are tasked with setting policy about how the NHS should operate within its budget.

Once again, views are diverse and often passionately held. One respondent said:



That is a ridiculous statement. It is practically impossible to separate demand from need. There is always more that clinicians can do, and want to do, which in every system in the world outstrips supply

CCG panel member

But another suggested that separating the decisions made by patient-facing clinicians completely from judgements about how best to use available funding (as implied by the question) is preferable:



Clinicians are not in the best position to decide – a decision to limit or differently manage public resources should be discussed and made at distance from the potential patient

Acute trust panel member

A third panellist's response reflects the concerns of patients and taxpayers at large, rather than simply a health service perspective:



I think we need a national debate over things that we now define as healthcare which are not illness, injury or life threatening, e.g. IVF

Acute trust panel member

There are a mix of national and local processes used to determine which treatments are funded by the NHS, including NICE appraisals and guidelines, commissioner priority setting and the Cancer Drugs Fund. Do you think this mixed approach is fair?

Opinion is split on this point, with under half of respondents (43%) agreeing that the current approach is very fair or quite fair, but more than a third (37%) viewing it as quite unfair or very unfair.

Once again, there is a wide range of different viewpoints. One respondent commented that the current approach 'isn't so much unfair as ineffective' (acute trust panel member). Another described it as 'too opaque to us as health care professionals – let alone patients, families and the general public' (ambulance trust panel member). However, a third person said: 'I can't think of a better system' (acute trust panel member).

Do you think the mixed approach of processes used to determine which treatments are funded by the NHS (described in the question above) is efficient?

Interestingly, when asked to consider the efficiency of the mixed approach, a greater proportion of respondents think it is inefficient, compared with those who think it is unfair. Exactly 50% view the approach as either quite or very inefficient. This contrasts with 32% who see it as quite or very efficient.

One respondent commented: 'It is bound to produce variability which is inherently not efficient' (Healthwatch panel member). Another said: '[It is] much improved upon having no processes and speeds up access to progress, but inequity still exists where guidance is not implemented' (acute mental health trust panel member).

Are you aware of any other rationing/priority-setting processes that you believe are better than those currently in use in the NHS (for example in other countries or public services)?

Only one in five respondents (20%) said they know of an international approach that they believe is better than current NHS practice. Respondents cited the US state of Oregon's approach, which includes a public consultation exercise where members of the public are invited to rank procedures in importance, and the International Liaison Committee on Resuscitation's (ILCOR) online public commenting process, which aims to provide transparent and rigorous treatment recommendations based on high-quality systematic evidence reviews.

If applicable, please share lessons you may have from the social care sector that could inform rationing/priority setting in the NHS.

The only approach currently adopted in social care that receives widespread support is personal budgets. One respondent said:



Self-directed support is an excellent model if providing better care more effectively and so at lower cost as opposed to rationing. I'm not sure this is directly applicable in the NHS, but the principle of putting the person in control of their care as a way of reducing costs is certainly one to explore in appropriate pathways

Healthwatch panel member

There is some criticism of other aspects of social care rationing. One panellist described it as: 'covert, arbitrary and rarely defensible' (CCG panel member).

Another said:

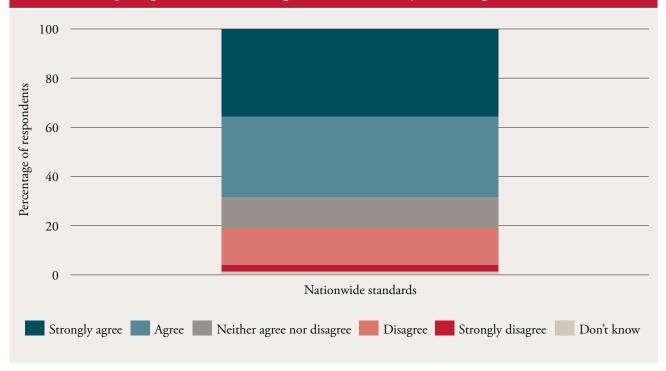


Social care should learn from the NHS in terms of the universality principle, rather than the other way round Healthwatch panel member

To what extent do you agree/disagree with the following statement: 'Patients should be able to access the same package of NHS services regardless of where they live in England'?

A significant majority of respondents (68%) either agree or strongly agree that patients should be able to access the same package of NHS services regardless of where they live in England (see Figure 2). More than a third (35%) strongly agree. Only 18% of respondents disagree or strongly disagree with this statement.

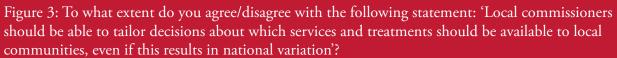
Figure 2: To what extent do you agree/disagree with the following statement: 'Patients should be able to access the same package of NHS services regardless of where they live in England'?

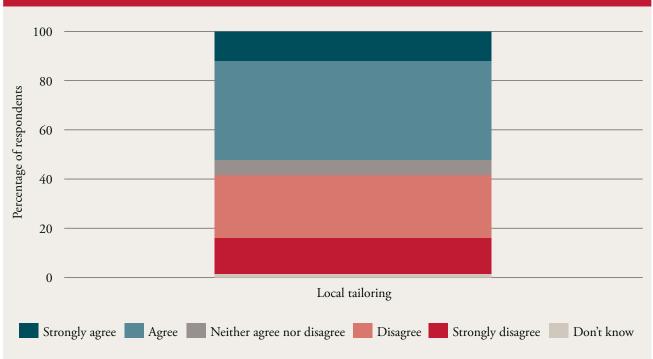


To what extent do you agree/disagree with the following statement: 'Local commissioners should be able to tailor decisions about which services and treatments should be available to local communities, even if this results in national variation'?

Even though this statement is at odds with the previous one, just over half of respondents (52%) either agree or strongly agree that local decision-making should be permitted, even if this results in variation (see Figure 3). The proportion disagreeing or strongly disagreeing is 41%.

Once again, the juxtaposition of responses to this and the previous statement illustrates the difficulty of designing a coherent approach to rationing that can command widespread support. It also demonstrates that senior leaders working in the sector can feel just as conflicted about the local decision-making versus national consistency debate as politicians and members of the public.





What is your opinion of the Cancer Drugs Fund?

The Cancer Drugs Fund is money set aside by the government to pay for cancer drugs that have not been approved by NICE for use in the NHS in England. We asked the panel which of the statements shown in Figure 4 most closely reflects their opinion about the Cancer Drugs Fund.

The majority of health leaders responding to our survey (59%) believe that the Cancer Drugs Fund should be wound up and responsibility for determining access to cancer drugs transferred to NICE (see Figure 4). Only 7% of respondents support retaining the fund in its present form.

Criticism of the fund is harsh, with one respondent describing the drugs it pays for as 'all about hope and nothing to do with evidence' (Healthwatch panel member). Another described it as a 'political slush fund' (acute trust panel member).

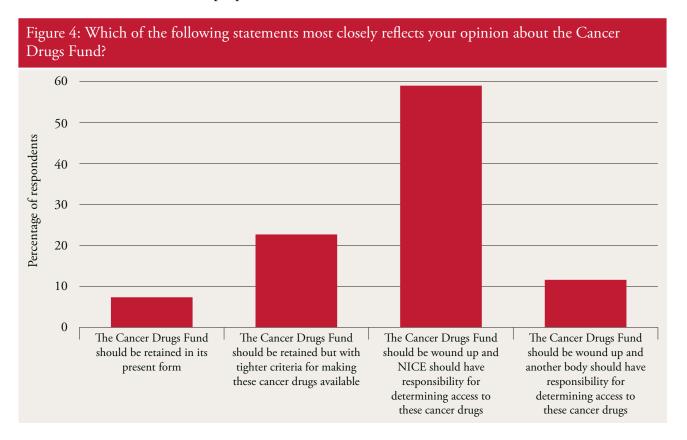
A third respondent stated:



I think we need a complete overhaul of how we make these decisions, as it feels confusing, and not fit for purpose

Acute trust panel member

On the basis of these responses, politicians should give serious thought to whether the fund is fit for purpose.



Views on health and social care - tracker questions

Each survey in our series asks a number of 'tracker' questions, to assess whether there are shifts in the views of the health and social care leaders over time. These questions cover access to health and social care, any perceived changes in the quality of both health and social care, and the long-term viability of comprehensive, publicly funded health care.

Given the small sample size, caution should be exercised in the interpretation of changes over time; however, we are including the comparisons between surveys as a general indication of perceptions among the panel members.

Since this time last year, do you think the quality of health care that patients receive from the NHS has improved, got worse or stayed the same?

Once again, a majority of panel members completing this third survey said they think that the quality of NHS health care has either improved or stayed the same (68%). But, in line with previous surveys, the proportion of respondents holding this view has decreased – this time by 11 percentage points between September and December 2014. Similarly, the number believing that the quality of health care has worsened increased by 10 percentage points over the same period, to 31%.

While overall confidence in the quality of NHS services is still high, this continued deterioration suggests mounting concern about NHS performance from some panel members.

Since this time last year, do you think that the quality of social care that service users receive from local authorities has improved, got worse or stayed the same?

More than three quarters (78%) of panellists responding to this latest survey said they think that social care has got worse over the last year, with only one respondent reporting an improvement. Another respondent told us that social care budget cuts are 'starting to have a real impact on services and also on the success of the integrated services project' (CCG panel member). Another panellist criticised the use of minimum wage and zero hours contracts for care staff as 'not the way to provide high quality care to highly vulnerable people' (Healthwatch panel member).

At the present time, which issue concerns you most regarding access to health and social care services in your local area?

Access to urgent health care services and securing access to social care are both identified as the most concerning issue by 30% of respondents. Most panellists completed the survey before January's media headlines about a crisis in Accident & Emergency (A&E), illustrating the fact that health leaders were viewing urgent care as a problem before trusts began declaring major incidents early in the new year.

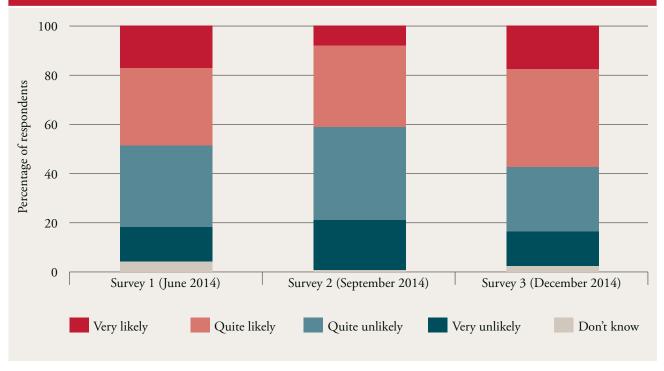
These two areas continue to preoccupy health leaders, having now been identified as the most concerning for three surveys in a row. Access to mental health services was selected as most important by a further 20% of respondents.

How likely do you think it is that comprehensive health care (excluding charges that already apply) will still be provided free at the point of use in England in ten years' time?

In response to this latest survey, a majority of respondents (58%) said they think it is either quite likely or very likely that comprehensive health care will still be provided free at the point of use in England in ten years' time (see Figure 5). Of these, 18% of panellists think it is very likely. This marks a return to the levels of certainty seen in June's survey (17%), in contrast with a dip to 8% in September. A further 40% think it is quite likely that the free offer will remain in place in a decade; in contrast with 40% who believe it is either quite unlikely or very unlikely.

The renewed optimism about the future of health care being free at the point of use may result from the Five Year Forward View, which made the case for increased funding to support the NHS.

Figure 5: How likely do you think it is that comprehensive health care (excluding charges that already apply) will still be provided free at the point of use in England in ten years' time?



Conclusion

The health and social care leaders' responses to the questions regarding rationing in the NHS clearly illustrate the challenges inherent in rationing policy. A majority of respondents express support for both local and national decision-making processes, even where these would be at odds with each other. A minority of respondents view the current processes as fair and efficient, but even fewer think that better approaches exist internationally, suggesting that current approaches to rationing may be seen as the best of a series of imperfect options.

The one area where respondents are able to reach a consensus is over the future of the Cancer Drugs Fund. The lack of support for this initiative among our panel members suggests that serious questions should be asked about its appropriateness. It is noticeable that panel members, despite their sector expertise, experience many of the same dilemmas about how best to ration care that exist in the wider public debate about these issues, which again illustrates the difficulty of arriving at neat solutions to these problems.

About the authors

Helen Crump is a Fellow in Health Policy at the Nuffield Trust. She has specialised in understanding NHS structural and system reform, regulatory policy and commissioning. Prior to joining the Trust, Helen worked at the Foundation Trust Network, where she led the organisation's regulatory policy programme, designing and implementing projects to assess the impact of new regulatory systems on NHS provider organisations.

Previously, she worked for the NHS Confederation's Primary Care Trust Network, undertaking qualitative research projects including a study into primary care trust commissioners' and GPs' experiences of practice-based commissioning. As a qualified journalist she has worked at specialist public sector titles such as *Health Service Journal*, *Local Government Chronicle* and *Pulse*.

Helen has studied qualitative and quantitative research methods, and has completed an MSc in Health Economics and Health Policy at the University of Birmingham.

Ruth Thorlby is a Senior Fellow in Health Policy at the Nuffield Trust. Her research interests include NHS reform, GP commissioning, accountability, international comparisons and health inequalities. Before joining the Trust she was a Senior Fellow at The King's Fund, where her publications included two major reviews of NHS performance as well as a range of briefing and research papers.

She was a 2008–2009 Harkness Fellow, based at Harvard Medical School, where she researched how physicians and health care organisations in the United States understood and tackled racial inequalities in the quality of health services.

Ruth has an MSc in Social Policy from the London School of Economics. Before moving into health policy research, Ruth was a broadcast journalist, working for the BBC World Service, and BBC News and Current Affairs programmes, including *Panorama*.



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