

Strategies to reduce inequities in access to planned care: an Ethics Review for Integrated Care Boards

Produced for the Midlands Decision Support Network by Professor Angie Hobbs, University of Sheffield

November 2022





Document Title	Strategies to reduce inequities in access to planned care: an Ethics Review for Integrated Care Boards
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Date	3 rd November 2022



Foreword: removing barriers to action

The evidence on health inequalities is depressingly familiar to anyone working in and around health and care services. It tells a story of failure.

For the last several decades, policy after policy has declared the need to 'tackle health inequalities'. Meanwhile, things have got worse. Notwithstanding some important successes in the early 2000s, the gap between rich and poor has grown. Incredibly, some groups in our society – notably poorer women – have even experienced declines in life expectancy. This is policy failure on both a grand and all too human scale.

The NHS contribution to these policy efforts has been variable. Partly this has followed the truth that healthcare plays a far smaller role in determining outcomes than wider conditions, such as employment, housing, crime, pollution (etc). Wider determinants matter more than health services, so it is here that change is needed. True. But is the NHS doing all it could?

Our analysis suggests not. In May 2021, the <u>Strategy Unit</u> – working on behalf of the <u>Midlands Decision Support Network</u> – released a <u>report</u> showing that access to elective care systematically favoured wealthier people over poorer people. We also noted that this had not always been the case, and that inequities resulted from recent choices. Our conclusion was stark: the NHS was exacerbating a problem it had set out to resolve.

Having described the problem, in May 2022 we turned to possible solutions. In this <u>report</u> we outlined a set of strategies that Integrated Care Boards (ICBs) could pursue: how could they reduce inequities in access to elective care? What might work?

In combination, our reports pointed to a problem and a set of solutions directly within the control of the NHS. Here was something that the NHS could do to reduce health inequalities. Given this opportunity, we also wanted to reduce the barriers to action.

One barrier mentioned to us was **legal**: were the strategies that we pointed to legally available to ICBs? So we commissioned a <u>legal review</u> from Hill Dickinson, which showed that our recommendations had a sound basis in law. In fact, their review opened up significant space for ICBs to act in a way that would far exceed our suggestions – and that could have ramifications far beyond this topic.

Another barrier was **practical**: could services systematically address inequities in the way they prioritised people for elective care? Here we worked with University Hospitals Coventry & Warwickshire (UHCW) NHS Trust, who have shown that <u>it is practically possible</u> to consider a broader range of factors – in addition to clinical need.

A further, related, barrier was **public acceptability**. Any approach to managing waiting lists necessarily prioritises some people over others. No 'neutral' approach is available; the question is *how*, not *whether*, to prioritise. Given this, what criteria and approaches would



local citizens suggest and support? Here, our partners Ipsos showed that <u>it is possible to</u> <u>engage people</u> in sophisticated and tricky choices, providing NHS decision makers with a practical steer.

Yet another barrier was **ethical**. Given that our recommended strategies involved trade-offs (as all strategies do), how should ICBs address the ethical questions of distributing resources to some people ahead of others?

That is the subject of this review from Professor Angie Hobbs.

As the world's first Professor of the Public Understanding of Philosophy, Professor Hobbs is adept at communicating complex ethical material in plain and compelling ways. So this review provides decision makers with a clearly argued and persuasive look at the ethical issues raised by our work.

The headline is that there is no ethical barrier to enacting the strategies we recommended. Professor Hobbs examines multiple potential ethical complications and problems; she concludes that they are all surmountable. And she goes further, ending with a practical process for making ethically sound decisions. Her work should provide ICBs with the confidence that they can make good, ethical decisions while addressing this contentious topic.

So where does this leave us? Are ICBs now more able to address inequities in access to elective care? Have we removed any barriers?

The Strategy Unit's reports mean that there is no barrier of ignorance. More is known about the problem and what solutions might entail. UHCW's work shows that practical barriers can be identified and overcome. Ipsos' work shows that public attitudes are not a barrier. Hill Dickinson's review showed that there is no legal barrier. And now Professor Hobbs' review shows there is no ethical barrier either.

This is an important topic where NHS action could make a real difference, supporting policy aims of creating a more equitable society.

What barriers, if any, now remain to doing so?

Peter Spilsbury

Director of the Strategy Unit



About the author

Professor Angie Hobbs is the Professor of the Public Understanding of Philosophy at the University of Sheffield. She gained a degree in Classics and a PhD in Ancient Philosophy at the University of Cambridge. After a Research Fellowship at Christ's College, Cambridge, she moved to the Philosophy Department at the University of Warwick; in 2012 she was appointed Professor of the Public Understanding of Philosophy at the University of Sheffield, a position created for her, and the only one of its kind in the world.

Angie's chief interests are in ethics and political theory from classical thought to the present and in ancient philosophy, and she has published widely in these areas; she has a particular interest in the ethics of flourishing and virtue (both ancient and modern), and whether this approach can help ease some of the tensions that often occur between rights-based approaches and approaches based on consequences, such as 'the greatest good of the greatest number'.

Her most recent publication for the general public is *Plato's Republic: a Ladybird Expert Book.* She has spoken at the World Economic Forum at Davos, the Athens Democracy Forum, the Houses of Parliament, the Scottish Parliament and Westminster Abbey. Angie is a Fellow of the Royal Society of Arts, was a judge of the Man Booker International Prize 2019, and was on the World Economic Forum Global Future Council 2018-9 for Values, Ethics and Innovation.

Angie contributes regularly in the media, including 25 appearances on *In Our Time* on BBC Radio 4; an appearance as the guest on *Desert Island Discs;* and contributions to *Private Passions* and *Test Match Special*.

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Summary of key points in this review

In May 2022, the Strategy Unit produced a <u>report</u> for the Midlands Decision Support Network looking at possible strategies that Integrated Care Boards (ICBs) could follow in trying to reduce inequities in access to planned hospital care.

The strategies outlined in that report carry ethical implications, and so I was asked by the Strategy Unit to review these implications from my perspective as a philosopher. **My review and the Strategy Unit analysis should therefore be read together**.

The main body of this report provides the detailed findings of my review, alongside an overview of the three main ethical approaches within western philosophy: rights-based, consequentialist and virtue ethics approaches.

The key points that emerge are that:

- None of the strategies proposed by the Strategy Unit is ethically unviable, and there is support for all of them from some elements of the NHS Constitution.
- However, there are still difficult ethical decisions to be made. These largely arise from ethical unclarities and tensions within the NHS Constitution itself, exacerbated by ethical tensions in the concept and application of Quality Adjusted Life Years (QALYs) and tensions between some rights-based elements of the NHS Constitution and the (largely) consequentialist goal of targets in furthering throughput.
- Consideration of an ethical approach focused on the wellbeing or flourishing of both patients and providers may help to ease (but not eradicate) some of these tensions. This is particularly in respect of waiting list prioritisation, shared decision making and decision coaches.
- Even though ethical tensions remain, **decision makers can be confident that they have the tools to make an ethically justifiable decision**. This confidence can flow from the thoughtful and careful application of an ethical process which involves:
 - a) Mature acceptance of inevitable tensions and uncertainty.
 - b) Public consultation and consent.
 - c) Open and accurate reporting of data and careful monitoring.
 - d) Willingness to adapt in the face of unexpected new data.
- If this process is followed with humility, integrity and thoughtfulness, then decision makers can have confidence that ethically justifiable choices will be made.



1. Introduction

In this section, I set out the brief, aims and background preparation for the review. I then turn to important definitional and conceptual starting points.

1.1 The brief for this review

The NHS 2022/23 priorities and operational planning guidance sets out that Integrated Care Boards (ICBs) will have four strategic purposes, one of those being to tackle inequalities in outcomes, experience and access. In the Health and Care Act 2022, ICBs are given responsibility for a wide range of functions to achieve these purposes.

Against this backdrop, the Strategy Unit composed its report for the Midlands Decision Support Network (MDSN) outlining a series of strategies for reducing inequalities in access to planned hospital procedures.

The report notes that:

'Reducing health inequality' must be one of this country's most stable policy aims. With peaks and dips in emphasis, it has been featured consistently in policy statements since at least the late 1990s. Yet outcomes have got worse. Gaps between rich and poor have widened. Defying a trend that began in late Victorian times, gains in life expectancy have stalled for poorer groups – and have even fallen for women from the poorest backgrounds. Variation in the experiences and outcomes of different communities during the COVID-19 pandemic served to bring this issue back into focus.'

The full report is available here: <u>https://www.midlandsdecisionsupport.nhs.uk/knowledge-library/strategies-to-reduce-inequalities-in-access-to-planned-hospital-procedures/</u>. Since my review is of the Strategy Unit's report, it is assumed that the reader has a copy to hand.

1.2 Preparation and aims

In addition to reading the Strategy Unit report, I also read: the NHS Constitution; a redacted draft version of the Ipsos report *Prioritising the elective care waiting list in Coventry and Warwickshire: findings from a public deliberation* (the final report compiled by Reema Patel, Devina Sanichar and Anna Beckett is <u>here</u>); the Hill Dickinson <u>legal review</u>; and Fraser Battye's series of <u>blogs</u> on decision making.

My aim in this review is to provide:



- a) A description of the context for the current ethical issues involved in strategies to reduce inequalities in access to planned hospital procedures.
- b) Clarification of the ethical questions, tensions and choices to be made.
- c) Suggestions for an ethical process which will ensure that, whatever choices are eventually made, they will be **ethically justifiable** ones. The ethical justifiability of the decision will not be impaired even if unwanted outcomes which could not reasonably have been foreseen mean that in the future an ICB wishes it had taken a different decision.

1.3 Important definitions and starting points

It is useful to establish some definitional and conceptual foundations at the outset. Specifically, we should know: why this issue matters; what the main philosophical approaches are when addressing it; and what terms I will use when describing it.

1.3.1 Inequalities, inequities, fairness: why should we care?

A working definition of fairness might be 'to attribute to each his, her or their due'. This rests on the basic assumption that each person matters as an individual and is more than a number. More precisely, this definition assumes that each person is a separate bearer of dignity and rights.

'Fairness' does not necessarily entail that in every case each person should receive an arithmetically equal portion of whatever is being distributed or receive precisely equal treatment.

Most would argue for some form of proportionality of treatment – whether in respect of need, or merit, or a mixture of both. If I go to the dentist, I do not want the dentist to say to me, before inspection, 'well, I have just removed two teeth from the last patient, so I will remove two of yours', irrespective of my need. Similarly, we do not think that every candidate for an exam should receive equal marks, irrespective of what they write: in this instance the criterion is not need, but merit.

However, there are cases where proportionality should result in equal treatment. If we are all of equal worth as fellow human beings, then we are all equally deserving of basic human rights; we should therefore have an equal opportunity to access basic goods such as healthcare.

When considering the fairness of distributions and actions, one can look at the impact on individuals and on the impact on various social groups. There can sometimes be tensions between the impact on individuals and groups - and also tensions between the impact on different groups (e.g. socioeconomic, age-related, regional). There can also be tensions



between appeals to fairness and to consequentialist approaches which aim at 'the greatest good of the greatest number'.

Some philosophers, including myself, believe that an ethical approach based on notions of flourishing or wellbeing and virtue can help reduce (though not entirely eliminate) some of these tensions. In what follows I aim to show that this is the case. Before doing so, it is worth looking briefly at alternative perspectives in ethics.

1.3.2 Ethical approaches within western philosophy

This review references three of the main ethical approaches within western philosophy:

- **Consequentialism** looks at the consequences of actions. The most well-known version is Utilitarianism, which aims at the greatest good of the greatest number.
- **Rights-based approaches** place great weight on fairness and view each individual as a separate bearer of rights and obligations not as a number to be added up in a Utilitarian sum.
- An ethics of flourishing and virtue focuses on the overall wellbeing of individuals and communities, and the moral and intellectual virtues needed to bring about wellbeing. (As we will see, there can be tensions between aiming at the wellbeing of an individual and of a community).

None of these three approaches assumes or requires a religious framework, although each can normally be viewed as compatible with most religions. This review is, however, grounded in western philosophy. It does not reference tradition- or religion- based approaches such as Buddhism, Confucianism, Shinto or Ubuntu.

These are also not the only ethical approaches within western philosophy, yet many would say that other approaches can usually be viewed as branches of them. For example, an ethics of care can fall under the umbrella of virtue ethics, while contractualism can fall under a rights-based approach. So, for the limited purposes of this review, I take these three approaches as my starting point.

1.3.3 'Inequalities' and 'inequities'

As far as I can tell, the NHS usually (though not entirely consistently), uses 'inequalities' to refer to any (usually quantitatively measured) inequalities in access or outcome, whether accompanied by a reasonable justification or not. 'Inequities' is then used to refer to unjustified inequalities.

In what follows I employ the same usage: I use 'inequalities' neutrally to refer to unequal numbers or amounts, which may or may not carry a pejorative value-judgement, whereas 'inequities' always carries a pejorative value-judgement.



2. The broader context for ethical decision making in the NHS

The approaches recommended in the Strategy Unit's report did not come from nowhere and do not exist in a vacuum. There is a broader context here: one which sets up its own ethical considerations and dilemmas. My review therefore begins by describing this 'ethical context'. I start by examining the NHS Constitution, before providing short remarks on Quality Adjusted Life Years (QALYs) and the use of targets as a managerial device.

2.1 The ethical context: the NHS Constitution

The NHS Constitution frames all decisions taken within the NHS. As such, it represents an important starting point for considering ethics.

At first glance, the number of ethical tensions and issues raised within the Constitution can appear a little daunting. The exploration below shows that the Constitution draws on a mix of ethical traditions. It is mostly fairness and rights-based, with injections of consequentialist and wellbeing approaches. This is not surprising. Most of us operate, without realising it, on a mix of these three approaches.

The important thing for ICBs is to be aware of this, and to acknowledge the inevitable degree of uncertainty and imprecision in which ethical decisions nevertheless have to be made.

Decision makers can also take heart:

- Later, in the conclusion of this review, I suggest ways of dealing with uncertainty, tension and imprecision. If the simple and clear process suggested is followed, then ICBs can feel confident that they will have made an ethically justifiable decision (even if new data prompt them to revise their decision).
- We can also note at the outset that the different ethical approaches within the Constitution offer a range of options for ICBs to employ providing that legally protected characteristics remain protected.

2.1.1 Rights-based approaches in the Constitution

Fairness and its concomitant respect for individual rights is a central theme of the NHS Constitution. This is clear from, for example, the Introduction ('to ensure that the NHS operates fairly and effectively'); Principle 1 ('respect their human rights'); Principle 3 ('respect' and 'dignity'); Principle 6 ('fair and sustainable use of finite resources'); and many of the Pledges on rights.



It should be noted that the Constitution talks both of fairness towards individuals and also towards groups. For example in Principle 1:

'a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population'

And also in 'Staff; your responsibilities':

'contribute towards providing fair and equitable services for all and play your part, wherever possible, in helping to reduce inequalities in experience, access or outcomes between differing groups or sections of society requiring health care.'

These quotes about fairness in general, and particularly the quotes about fairness towards groups strongly support the aim of reducing inequalities in access to planned hospital procedures. However, it should be noted that there could be situations in which being fair to a group might work against fair treatment of an individual in a different group.

There could also be clashes between fair treatment of different groups, particularly if one of the distinguishing features is not listed as one of the protected characteristics in the Equality Act 2010 or the Health and Care Act 2022.

The obvious example here is socioeconomic disadvantage (and indeed it is debatable whether socioeconomic disadvantage *could* be classed as a 'protected characteristic' even in new legislation). As things currently stand, it could be argued that a wealthy but aged group would need to take priority over a socioeconomically disadvantaged group, given that age is a protected characteristic and socioeconomic disadvantage is not.

Finally on this point, the Constitution talks of the importance of transparency e.g. Principle 7:

'The system of responsibility and accountability for taking decisions in the NHS should be transparent and clear to the public, patients and staff'.

This is admirable, though it needs to be acknowledged that if subsets of groups find out the reasons behind e.g. waiting list prioritisation, without having been consulted previously, some of those within them may feel patronized, and trust may be eroded and consent damaged.

2.1.2 Consequentialist approaches in the Constitution

Furthermore, at times the Constitution seems to take a consequentialist approach. Here the focus is on overall outcomes. For example, Principle 6 *The NHS is committed to providing best value for taxpayers' money*, which requires that the use of finite resources be not only fair but 'effective'.

So there could also be tensions between an approach which focuses on fairness and rights, and an approach which focuses on consequences. For example, it may be less expensive to



focus on more socioeconomically privileged groups, with fewer access problems and possibly fewer comorbidities; this approach might be effective but unfair.

However, there is also an unclarity about the phrase 'best use of taxpayers' money'. Does it simply refer to that portion of taxpayers' money which is allocated to the NHS, or to taxpayers' money overall? If the latter, it may in fact be more cost effective in the medium-to long-run to prioritise a disadvantaged group in some contexts regarding access to planned hospital procedures. (Indeed, as the Strategy Unit report notes, it may even be more cost effective in the medium-to long- term in respect *only* of those monies allocated to the NHS, as it may reduce the need for emergency care.)

In addition, within the consequentialist approach in parts of the Constitution, there is occasionally talk of quality as well as quantity. This mirrors a tension within the most well-known version of consequentialism itself, Utilitarianism (with its maxim of: 'the greatest good of the greatest number').

The founder of Utilitarianism, Jeremy Bentham, devised a solely quantitative system, but his pupil, John Stuart Mill, wanted to consider quality too – a move which illuminated the difficulty of introducing quality into calculation. Personally, I am in favour of considering quality, so long as there is a clear understanding that this will make calculations less precise (although a good deal of precision can still be reached).

It also needs to be acknowledged that there is also some inevitable uncertainty and imprecision even within a purely quantitative Utilitarian approach. This is because one of the yardsticks is the future extent of the consequences of one's action - yet none of us can know the future!

There can also be a tension within Utilitarianism between everyone counting as an equal unit, and some people – such as health professionals or carers - being considered to provide more 'utility' (i.e. good). The (usually unacknowledged) logic of this is that such providers of utility are themselves worth more in a Utilitarian calculation.

This is a question which may be relevant in discussion of waiting list prioritisation; although in my view it can be an ethically dangerous route to take. Instead, it is perhaps better to consider the role of health professionals and carers from the point of view of the damage that may be done to those they care for if they are out of action, rather than (even if only implicitly) viewing providers of care as intrinsically worth more than other human beings.

2.1.3 Considerations of 'wellbeing' in the Constitution

The very first sentence of the Introduction to the Constitution talks of improving wellbeing as well as health. This is a term which occurs within the third basic approach in western ethical theories outlined above, namely an ethics of flourishing, wellbeing and virtue.



I suggest in 3.2.1 that this approach may be helpful in shared decision making and with decision coaches and also in easing the difficulties – although it will not eliminate them - connected with waiting list prioritisation. It may also have some value in zero-sum redistribution.

2.2 The ethical context: a note on QALYs

A number of ethical questions have been raised about QALYs. Is it really health or overall wellbeing that is at issue? Is it really possible to measure quality quantitatively? How to decide if the patient cannot be consulted?

The question that most immediately concerns ICBs in respect to reducing inequalities of access to planned hospital procedures is whether QALYs are inherently skewed against certain groups, such as the disabled or – the immediate concern here – socioeconomically disadvantaged groups. There is a real risk that, however well-intentioned, as implemented at present QALYs can unintentionally reinforce the status quo. The risk is likely to be intensified if resource use is added in.

2.3 The ethical context: a note on Targets

The same concern about reinforcing the status quo can be raised in respect of some targets (almost always conceived within a consequentialist framework).

This is particularly the case if they concentrate on treating the maximum number of people in the shortest amount of time and/or in the most cost-effective way. Socioeconomically deprived groups may take longer – and so cost more money – to reach; these groups may also contain patients with more comorbidities.

This is one of the main reasons it may be preferable to concentrate on process rather than targets or outcomes (although of course outcomes should be scrupulously monitored and discussed, and process re-adjusted as necessary).



3. Review of approaches suggested in the Strategy Unit report

Having provided a summary of the ethical context, I now turn to examining the Strategy Unit report itself.

My review is a commentary. It is therefore **assumed that readers will have a copy of the Strategy Unit report to hand as they navigate what follows.** The report is available here: <u>https://www.midlandsdecisionsupport.nhs.uk/knowledge-library/strategies-to-reduce-</u> <u>inequalities-in-access-to-planned-hospital-procedures/</u>. And, to aid navigation, I have *highlighted* the section of the Strategy Unit report (hereafter: 'the report') under review.

Before entering further detail, it is important to note the main headline of my review: no strategy suggested in the report is ethically unviable.

Yet there are caveats. This section concentrates on outlining those caveats, highlighting those strategies which are particularly helpful in respect of ethically responsible decision making. Where no comment is made about a particular strategy, it should be understood that it is ethically unproblematic.

3.1 The nature of the challenge

The report rightly notes that a short-term strategy to reduce waiting lists could work against a long-term strategy to reduce inequalities, and that there will usually be a trade-off between equity and efficiency. It rightly recommends asking the population, their representatives and healthcare professionals / organisations what trade-offs they would be willing to make.

In **section 1.4**, the report rightly suggests that ICBs consider whether 'levelling-up', 'levelling-down' or 'zero-sum' options might be most appropriate to different scenarios. From an ethical perspective:

- Levelling-up is ethically attractive if money, time and resources are available, but beware of the impact on other public services and also the impact on the wellbeing of healthcare professionals. Nevertheless, levelling-up should be considered very seriously for the most effective procedures.
- Levelling-down can be a useful short-term measure in emergency situations such as a pandemic. It may also have a role to play in procedures of limited clinical value.
- **Zero-sum redistribution** could also be attractive in the case of treatments of limited clinical value. An approach based on flourishing could be helpful in the case of zero-



sum redistribution amongst patients in the same class of clinical need, and providing protected characteristics are not discriminated against.

It should be noted that both levelling-down and zero-sum redistribution will result in a reduction of activity for some groups. As having something taken away can have adverse psychological affects (loss being more keenly felt than gain), the wellbeing of those so concerned may also be adversely affected. But it is not clear that this would outweigh the overall benefits of short-term levelling-down in an emergency, or of zero-sum redistribution in cases of limited clinical value.

With respect to how to balance any of these options against the needs of other forms of health and social care, it is recommended that the public are consulted.

3.1.1 The problem of starting from existing inequities

'The national strategy is framed in terms of managing down waiting lists and times. Given that people living in more deprived areas are often underrepresented on the waiting list, this strategy may represent an additional obstacle to equity.' (**p.21**)

This is surely correct, and the reasons for underrepresentation on waiting lists need to be examined with great care. Although the report states that inequalities tend to emerge at later stages of the care pathway, it seems highly likely that the hidden inequalities much earlier in the care pathway – before waiting lists are even formed – are of profound ethical significance and influence.

3.2 Potential approaches to reduce inequities

I now turn to examine specific approaches suggested by the report.

3.2.1 Identification and referral to secondary care

This relates to section 3.2 of the Strategy Unit report

The report rightly notes that waiting for those with concerning symptoms to present is unreliable and inconsistent. The report therefore considers placing the responsibility for initiating care with the health service. This proactive approach is to be commended, providing it is integrated with measures to encourage take-up rates.

It is very much to be recommended that the GP and patient share in the decision making process. This is one of the points in the care pathway where an ethics of flourishing / wellbeing could be particularly helpful, taking the whole person and their life into consideration. However, it must be acknowledged that such an approach takes time: more GP time might be needed. Time might also be in short supply for a patient, particularly if they are doing more than one job to make ends meet.



Decision aids and decision coaches are also to be recommended, if resources (including language skills as well as personnel and money) permit; this too is an area where an approach based on overall flourishing could be helpful.

In respect of adjusting referral thresholds downwards, or loosening eligibility criteria, it is ethically very important that such adjustments only be made in respect of the criteria used to ration treatments, and not the criteria that relate to indications of risk.

3.2.2 Pre-admission assessment and management

This relates to section 3.3 of the Strategy Unit report

It is to be recommended that more studies are undertaken to look at the equity impact of telephone and video appointments. For those in socioeconomically disadvantaged groups, no need for transport and less time off work could well be a plus; but this would need to be balanced against the fact that perhaps fewer in these groups have access to the necessary technology.

It is undesirable that at present free at the point of need non-emergency transport to and from hospital only appears to be provided to those with mobility issues, and not on economic grounds. The Healthcare Travel Costs Scheme (HTCS) is retrospective, which could well pose problems (it is also a scheme not widely known).

Out-of-hours appointments are clearly helpful to those on zero-hours contracts and in insecure employment, but in addition to issues of financial resources, it must be considered whether such out-of-hours appointments place an intolerable burden on health care professionals: their wellbeing matters too!

3.2.3 Decision to treat

This relates to section 3.4 of the Strategy Unit report

The same points apply regarding shared decision making and decision aids and coaches in secondary care as in primary care (3.2.1). This is another point on the care pathway where an approach based on flourishing / wellbeing could be helpful.

If the resources are available, it is certainly a good idea to reimburse a provider at a higher rate to support patient A over patient B, if it costs the provider more to support A to achieve a given outcome.

There are clearly serious ethical issues to consider regarding patient payments: they must be framed in terms of covering out-of-pocket expenses, rather than encouraging people to have surgery, or people might be tempted to have unnecessary procedures.



3.2.4 Waiting list prioritisation

This relates to section 3.5 of the Strategy Unit report

This is clearly the point in the care pathway where the toughest ethical choices arise. It is therefore where I focus most attention.

The starting point is that current approaches are already full of difficult ethical choices; the point is that any proposed change might make the choices more visible, and thus feel more risky.

However, there is surely room for manoeuvre in the ordering of patients within a particular class of clinical need. And this is one of the main areas where an ethical approach based on overall flourishing might be worth considering, particularly – though perhaps not exclusively - in respect of non-clinical factors, taking into consideration social/ familial/ educational/ occupational context.

For example, if two patients within the same class of clinical need are both waiting for a knee operation, one might want to ask whether there is a family member or employee who can drive them to where they want to go, or bring in and put away groceries that they have ordered. Do they in fact have the technology to order online? Are they able to do paid work at home? Do they have ready access to a green space, such as a garden?

In other words: how much is their overall wellbeing affected by the wait?

There might need to be a separate discussion about whether such issues might only be relevant if two patients have been waiting for the same length of time, or whether in some cases it might be acceptable for patient A to be treated ahead of patient B who has been waiting a little longer, if the impact on wellbeing is felt to be severe.

In these cases, there would need to be clear guidelines about how long 'a little longer' can be, as it would be very unfair if the treatment of a person in a well-resourced situation was endlessly delayed to make way for a constant stream of less privileged people.

In this example, the question is not how many QALYs might be predicted – which can tend to favour those in socioeconomically privileged circumstances – but simply the extent to which a particular procedure, or delay in that procedure, would affect, or is affecting, immediate wellbeing.

Although this overall wellbeing approach does not make direct reference to the patient's socioeconomic status, in practice socioeconomic status is likely to influence some – though by no means all – of the answers. One might want to consider not only the flourishing of the patients themselves, but also of those they care for.



If prioritisation is based solely on the clinical impacts of treatment, rather than the whole person and their whole life, then this criterion may work against some in socioeconomically deprived areas who may have more comorbidities.

However, whether prioritisation is based on overall wellbeing or simply on likely clinical impact, it must be accepted that decisions will inevitably be taken in an environment of some uncertainty, as positive outcomes are not so consistently recorded (and in any case SORT and ACHE are currently used to decide on a planned intervention, not – so far – on waiting list prioritisation).

Furthermore, as noted above, as soon as one brings quality of life issues into consideration, precise quantitative measures cannot be achieved. Any system which aims to ascribe quantities to qualities will inevitably therefore be approximate (though it may certainly still be worth doing, as in the case of the University Hospitals Coventry and Warwickshire (UHCW) NHS Trust Clinical Priority Tool, which is based on both clinical and non-clinical factors).

Also, in the <u>lpsos report</u> referred to above (which was done in light of UHCW's approach), participants were concerned that subjective responses concerning pain etc. could be 'gamed'. They also expressed concern about unintended consequences.

Participants in the lpsos research were also particularly concerned about prioritisation based on certain non-clinical factors. They were in favour of taking overall psychological wellbeing and quality of life into account, but more hesitant about certain factors viewed as 'social', including living in a deprived area.

In practice, however, as noted above, wellbeing and social factors will be very closely interconnected, so considering the quality of life of a patient, and taking action in consequence, will in many cases involve an impact on a particular socioeconomic group.

Although there was not complete agreement in the Ipsos research about what constituted fairness in respect of waiting list prioritisation, it was nevertheless felt very strongly that fairness is of fundamental importance. Prioritising waiting lists in a way which was locally felt to be unfair would be unlikely to achieve its aims.

The findings from Ipsos suggest, as an alternative to waiting list prioritisation, giving more support to those on waiting lists in socioeconomically disadvantaged groups alongside efforts to increase access. More support, however, does not have to be viewed simply as an alternative: more support to certain groups is to be strongly recommended, whether waiting list prioritisation is to be adjusted in respect of non-clinical factors or not.

Finally, given the concerns expressed in the Ipsos report, and the fact that there are no easy or uncontroversial answers here, it is strongly recommended that ICBs consult widely before developing any rankings which involve non-clinical factors, to ensure that they are providing care in an environment of consent and trust.



3.2.5 Treatment accessibility

This relates to section 3.6 of the Strategy Unit report

(See 3.2.2 on the importance of free at point of need transport system).

Regarding minor surgery in primary care, the positives of proximity and convenience need to be balanced against both the importance of not taking GPs away from disease identification and referral, and the potential impact on the wellbeing of the healthcare professionals themselves.

The same issue regarding the potential strain on practitioners also applies to evening and weekend surgeries (which clearly can be very helpful to patients, particularly those on zero-hours contracts).

3.3 Developing a strategy

This relates to section 4 of the Strategy Unit report

The report acknowledges that finite funding and limited management capacity mean that it is not currently possible to implement all these options. It offers practical and clearly communicated advice on how to design a health system to select from the options, rightly emphasising that 'to prioritise everything is to prioritise nothing'. *Figure 13* also provides a very helpful table of points of intervention and types of intervention available at each point.

Sample strategy 1 recommends targeting decision making, between patient and clinician in particular. This could be effective, but care will need to be taken given likely trades in clinician time (giving more to some patients than others).

Sample strategy 2 recommends a fully digital approach. This could be helpful, but digital technologies are not taken up equally across socioeconomic groups, which could exacerbate the problem.

Sample strategy 3 recommends pulling the financial levers. This is an ethically very tricky balance: if they are too high, they risk distorting clinical practice away from patients' best interests. The strategy also risks reducing individuals and organisations to economic actors, commodifying actions that should be valued for other reasons.

Sample strategies 4 and 5 are ethically unproblematic in my view.

The report suggests that a health system select a strategy based on its performance against fidelity, coherence, theoretical effectiveness, feasibility and – crucially - public acceptability. The Ipsos research underscores the point about public acceptability, particularly in respect of non-clinical factors. The technocratic nature of the NHS (understandably) works against the making of values-based decisions, so engaging with local populations will be vital to provide ethical legitimacy.



3.4 Measuring progress

This relates to section 5 of the Strategy Unit report

Detailed studies will take time to design and implement. What can be done more quickly? The Report rightly emphasises the importance not only of having clear arrangements for monitoring and reviewing, but also acting upon the results. It gives excellent advice (**p.55**) on how to allocate time in the relevant meetings – do not let the desire for perfection (e.g. on data quality) be the enemy of the good. I return to this point at the end of the review.

The report rightly cautions (5.3.4) about the need to be wary of targets:

'Managers, under pressure to deliver a target value, can lose sight of the real change that was intended and instead subtly change the way the data is reported. This can mean that decision makers receive an unrealistic view of the improvements that have been made and miss opportunities to take corrective action. On balance, targets have few direct benefits, but they do carry risks.'

The open, full and accurate reporting of data is vital, and great care must be taken not to engineer a system which puts managers under pressure to distort the data (such distortion can even be unconscious if the manager is under pressure).

However, although number targets are often unhelpful, it is I think very important that an ICB has a clear, overall vision of what they think individual and communal wellbeing/ flourishing consists in, and a clear vision of their overall aim. Even if they accept that this aim is unlikely to be fully realised, it is still very important to have a clear picture of the ideal that one is working towards.



4. Concluding advice

Some elements of the NHS Constitution offer strong support for the aim of reducing inequalities in access to planned hospital procedures, and the strategies suggested in the Strategy Unit's report for the Midlands Decision Support Network offer a commendable range of options for decision makers to consider if they elect to work towards this aim.

None of the options is ethically unviable in itself, although care will need to be taken not to discriminate against any of the groups with protected characteristics (and it is noted that socioeconomic disadvantage is not currently classed as a protected characteristic).

For a decision to be ethically justifiable, care will also need to be taken to focus in the first instance on process rather than outcomes - although of course scrupulous and honest monitoring of outcomes must be ongoing, and processes regularly reviewed in the light of outcomes.

The process for an ICB suggested in this Ethics Review (in respect of non-clinical factors in particular, though not exclusively so) is:

- a) Gather the best information available and analyse the data.
- b) Reflect and discuss; decide on whether the wider community should be consulted and, if so, what questions to ask; such ethical discussions should be normalised, and diverse views should be encouraged.
- c) Consult with a wide and diverse range in the community. Do so with clear acknowledgement of tensions, trade offs and ethical difficulties.
- d) Analyse the results and discuss again. Consider whether a focus on the wellbeing of patients and providers might provide a helpful angle, providing the human rights of all have been met, and those with protected characteristics are not being discriminated against. Here, it is not precisely clear in practice what 'discriminated against' might involve. For example, would investing in poor, young people count as 'discrimination against affluent, older (protected characteristic) people? Nonetheless, ICBs do at least need to be aware of protected characteristics in their decision making.
- e) Take a decision, knowing that if this process has been followed with integrity the decision will be an ethical one, even if unexpected outcomes cause the ICB in the future to wish that a different decision had been taken.

This process needs to be undertaken in acknowledgement of the following points:

• Although the NHS Constitution understandably mainly employs an ethical approach based on fairness, rights and respect, it also at times employs a consequentialist approach based on the greatest good of the greatest number (and targets and



QALYs are usually consequentialist). Tensions can arise between a fairness/ rights approach and a consequentialist approach. Sometimes these tensions are irresolvable; at times one just has to choose which approach to adopt. And the weight the NHS Constitution accords fairness and rights suggests that in these instances of irresolvable tensions, then fairness/ rights should usually be preferred to the greatest good of the greatest number. (Even here there is also a real question about how you would measure the 'greatest good': number of people or overall QALY gains?).

- However, providing the basic human rights of all are met, and groups with protected characteristics are not discriminated against, there may be situations – particularly with respect to shared decision making, decision coaches and waiting list prioritisation – where taking an approach based on the overall wellbeing or flourishing of the patient can be helpful.
- There can also be irresolvable tensions within a fairness approach. There can be tensions between fairness to different groups, or between groups and individuals (as noted, the NHS Constitution mentions fairness towards both groups and individuals). Again, the ICB simply needs to acknowledge and discuss these tensions. And again, providing basic human rights are met, and those with protected characteristics are not being discriminated against, then decisions regarding e.g. waiting list prioritisation can sometimes be made by looking at the overall wellbeing or flourishing of patients at the same point of the scale of clinical need. If the process is followed, and those groups with protected characteristics are not discriminated against, the MHS Constitution.
- Within a consequentialist approach, there can be tensions between quantity and quality. Again, this should not daunt decision makers; it should simply be understood. The point is that all these approaches – whether based on rights and fairness, the greatest good of the greatest number or wellbeing/ flourishing – are ethical approaches. So long as the differences and possible tensions are acknowledged and discussed, it will be up to each ICB to decide which approach to prioritise in any particular situation.
- The underlying point here is that decision makers need to accept that they are often making decisions in an environment where there can be no single certain answer. In addition to the tensions both within and between the different ethical approaches outlined above, uncertainty over future conditions and outcomes is also relevant here.
- The fact that an ethical decision has to be taken in conditions of ambiguity and uncertainty does not prevent it from being an ethically justifiable one. The key is to



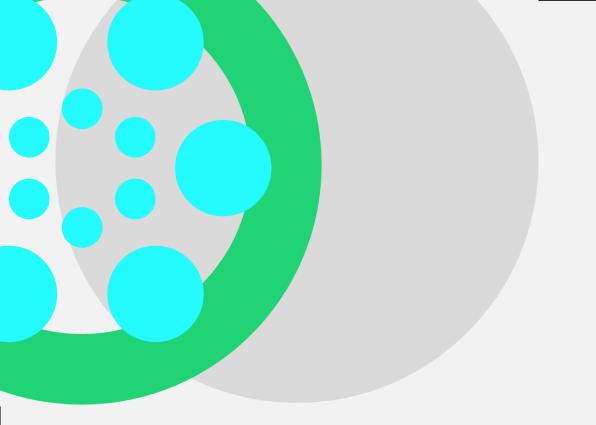
follow a process with care and integrity, and for decision makers to act with qualities of humility, integrity and thoughtfulness.

- Consultation with the public, patients and staff will often be vital for two reasons:
 - 1) A diverse range of voices and experiences will usually make for better ethical decision making, particularly with respect to non-clinical issues; and
 - 2) It is very important that care is provided with the consent of the relevant group or subgroup. This matters in itself and it will also assist the aims of transparency and accountability, particularly in respect of sensitive issues such as the criteria for prioritising waiting lists, if those criteria have the broad consent of the target groups.

In sum, the Strategy Unit report offers clear, practical and ethically responsible suggestions at each step of the care pathway for ICBs who want to reduce inequalities in access to planned hospital procedures.

Absolute certainty can very rarely be reached in ethical decision making but that does not prevent ethically responsible decisions being taken.

Do not let perfection be the enemy of the good!





Midlands Decision Support Network

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