HARNESSING DELIBERATIVE REGULATION TO ADDRESS INEQUITIES IN ACCESSING HEALTHCARE SERVICES IN ENGLAND

ABSTRACT

System level decisions around the commissioning and provision of healthcare services in England have contributed to barriers in accessing the NHS. In this article, we ask how to better regulate resource allocation to ensure greater equity in access to healthcare services. First, we focus on the Health and Care Act 2022 which, drawing on principles of *deliberative* regulation to address health inequalities, initiates a shift away from previous regulatory approaches towards a collaborative decision-making model. We then shed light on the systemic factors creating and maintaining access barriers by considering shortcomings in previous regulatory approaches. With these in mind, we consider whether deliberative regulation - providing communities with resources to create normative solutions to intrinsic issues - could help address these systemic challenges. To assess the potential of laws or policies to achieve greater equity in healthcare, we also introduce an evaluative framework based on deliberative principles. We apply this framework on a case study of an Integrated Care System to gauge the extent to which the Health and Care Act 2022 has indeed been effectively adopting a deliberative approach by intentionally engaging marginalised communities in decision-making and devising accountability mechanisms for the allocation of healthcare resources.

KEYWORDS: Deliberative Regulation, Health Equity, Integrated Care Systems, Marginalised Groups, NHS; Resource Allocation; Access Barriers.

I. INTRODUCTION

In the English National Health Service (NHS), structural and systemic issues have created barriers in accessing healthcare services, leading to differences between groups and generating

variations in health outcomes in the population[1], but especially in marginalised communities[2] (*inter alia* racialised communities, gender diverse people, people with disabilities, people with precarious migration statuses or people affected by high level of deprivation and poverty). Although indirectly, these barriers have a compounding effect when interacting with wider determinants of health,[3] with poorer health outcomes and further inequalities in avoidable mortality of affected individuals.[4] The SARS-COV-2 pandemic has also laid bare the lack of understanding of marginalised communities' complex lived experiences and their inability to secure quality healthcare services without substantial personal costs.[5]

We contend that these challenges do not only stem from the inadequate delivery of services, but from the type and quantity of services that are being commissioned for a diverse population in England. While resource allocation decisions happen at the bedside, we argue that higher system-level decisions around the commissioning and provision of healthcare services have more of a system-wide impact in establishing and perpetuating barriers. To meaningfully address access barriers, we need to shift our attention away from individual rights that are mostly focused on an individual's capacity to access services, to focus on system processes, such as the commissioning of services, which can address the structural causes giving rise to health inequality.[6] In short, we must look more intentionally at redesigning the normative frameworks for the regulation of resource allocation activities.

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[1] Patrick Hutt and Stuart Gilmour, 'Tackling Inequalities in General Practice' (2010) The King's Fund; Michael Marmot and others, 'Health and Equity in England: The Marmot Review 10 Years On' (2020) < www.health.org.uk/publications/reports/the-marmot-review-10-years-on> accessed 8 July 2024.
[2] Julian T Hart, 'The Inverse Care Law' Lancet (1971) 297 (7696) 409.
[3] Ronald Labonte, 'Health Promotion and Empowerment: Practice Frameworks' (1993) Centre for Health Promotion and PartipACTION.
[4] Marmot (n 1).
[5] Adrienne Yong and Sabrina Germain, 'Ethnic Minority and Migrant Women's Struggles in Accessing Healthcare during COVID-19: an Intersectional Analysis' Journal for Cultural Research (2002) 26(1) 65.
[6] Norman Daniels, *Just Health: Meeting Health Needs* Fairly (CUP 2012) 81; Christopher Newdick 'Health Equality, Social Justice and the Poverty of Autonomy', Health Economics, Policy and Law (2017) 12 411.

In his foundational work, Selznick defines regulation as a public agency's use of a device to exert control over an activity because of its importance or value to a community.[7] Regulation can curtail or prevent some undesirable behaviours or, conversely, promote or facilitate practices, potentially infringing on a market's free allocation of goods. With a legitimate rationale underpinning the intervention, regulation can condition social activities.[8] Regulation can also lead to an information gathering exercise and standard setting practices to meet a commonly defined objective such as distributive justice.[9]

Priority setting, or 'limit-setting', for the allocation of healthcare resources is by nature a regulatory process.[10] The British State has used regulatory approaches to establish rules for the financing and delivery of healthcare services in England over the past 70 years, but these approaches have failed to fully realise *equity* in healthcare, let alone *equal access* to the NHS.[11] Equality in access aims to provide all with the same entitlement and opportunity to access healthcare services. Equity in healthcare focuses on remediable differences and aims to prioritise the needs of the most disadvantaged to ultimately realise the same health outcomes for all.[12]

In this article, we ask how we can better regulate resource allocation to tackle health inequalities by ensuring greater *equity* in access to healthcare services. We propose to address this question adopting a socio-legal methodology drawing on political history, law and management studies to shed light on a new mode of governance for the allocation of healthcare

[7] Philip Selznick 'Focusing Organisational Research on Regulation', in Roger Noll (ed), *Regulatory Policy and the Social Sciences* (University of California Press 1985).
[8] Robert Baldwin and others, *Understanding Regulation: Theory Strategy, and Practice* (2nd edn, OUP 2012).
[9] Tony Prosser, *The Regulatory Enterprise: Government, Regulation, and Legitimacy* (OUP 2010) 4; Julia Black, 'Critical Reflections on Regulation' 27 (2002) Austl J Leg Phil 1.
[10] Norman Daniels and James E Sabin, *Setting Limits Fairly: Can we Learn to Share Medical Resources?* (OUP 2002).
[11] Martin Powell and Mark Exworthy, 'Equal Access to Health Care and the British National Health Service' (2003) 24 51 Policy Studies ; Anna Dixon and others, 'Is the NHS Equitable? A Review of Evidence' (2003) LSE Health and Social Care Discussion Paper Number 11.
[12] Harleen Kaur and Sabrina Germain, 'Health Disparities, Equity, and Pandemic Ethics; in Elizabeth C. Romanis and others (eds), *Diverse Voices in Health Law: Important Perspectives* (forthcoming, 2025).

resources. In the first part of the article, we focus on the Health and Care Act 2022, as its new collaborative approach to decision-making marks a clear departure from the regulatory approaches historically adopted for the allocation of healthcare resources. With the objective of reducing health inequalities, the reform embraces elements of *deliberative regulation* - a model suggesting that a regulator provides regulatory subjects with resources to develop normative solutions to an issue that intrinsically affects them. This prompts us to further examine the theory behind this regulatory approach to determine whether it has the potential to tackle some of the shortcomings of previous approaches.

In the second part of the article, we look at these shortcomings, identifying three systemic factors that, we argue, have contributed to establishing and perpetuating barriers to accessing healthcare services in England. Our typology is derived from our analysis of key reforms, laws and policies that have guided the allocation of resources for the commissioning, provision and delivery of NHS services up until 2022.

Having these three systemic factors in mind, in the third part of the article we fully consider the theory of deliberative regulation as advanced in law by Black [13] and others.[14] Although this theoretical approach to regulation does not offer an operational blueprint for decision-making, it provides a critical approach to expose decision-making distortions.[15] We use deliberative theory for this very purpose and to form the basis of an evaluative framework. The framework we flesh out provides a tool to assess law and policy processes for the commissioning and provision of healthcare services and to understand whether new and current propositions can correct the systemic factors stemming from the failure of previous regulatory approaches.

[13] Julia Black, 'Proceduralizing Regulation: Part I' (2000) 20 (4) Oxford Journal of Legal Studies 697; Julia Black, 'Proceduralizing Regulation: Part II' (2001) 21 (1) Oxford Journal of Legal Studies 33; Julia Black, 'Regulatory Conversations' (2002) 29 (1) J. of Law and Society 163.
[14] Cary Coglianese and Evan Mendelson, 'Meta-Regulation and Self-Regulation' in Robert Baldwin and others (eds.), *The Oxford Handbook of Regulation* (OUP 2010) 150.
[15] Ian Rees Jones, 'Health Care Decision Making and the Politics of Health' in Graham Scambler (ed.), *Habermas, Critical Theory and Health* (Routledge 2001).

In the final part of the article, we consider the Frimley Integrated Care System as a case study and, using our evaluative framework, analyse its governance structure (which reflects the changes brought about by the Health and Care Act 2022) to understand whether, and to what extent, it has adopted a deliberative approach to resource allocation to address the significant health inequalities present in its diverse and underserved population.[16]

II. THE HEALTH AND CARE ACT 2022: FULLFILLING AN OLD MANDATE WITH A NEW APPRAOCH

Historically, the allocation of healthcare resources in England has followed two regulatory approaches. At the inception of the NHS, the *regulation for social purpose* required that structures be put in place to pursue a public interest objective - universal access to healthcare - through collective financing and the national organisation of services.[17] Subsequent waves of healthcare reforms brought in the *regulation for efficiency and patient choice* which introduced competitive forces in the healthcare sector, with a focus on performance that aimed at increasing patient choice.[18] Arguably, both regulatory approaches have failed to achieve an equitable access to healthcare services.[19] The formal legal duties to reduce health inequalities in England bestowed on the NHS in 2006 with the National Health Service Act,[20] re-affirmed in 2009 with the NHS Constitution,[21] and set as a priority in the NHS Long Term Plan 2019[22]

[16] Priya Kumar, 'Healthcare and Prevention Through a Multi-Generational Household Approach' NHS England (2023) <www.england.nhs.uk/blog/healthcare-and-prevention-through-a-multi-generational-household-approach/>.
[17] Mike Feintuck, 'Regulatory Rationales Beyond the Economic: In Search of the Public Interest' in Robert Baldwin and others (eds) *The Oxford Handbook of Regulation* (2010) 43.
[18] Christopher Newdick, *Who Should We Treat? Rights, Rationing, and Resources in the NHS* (2nd ed, OUP 2005).
[19] Anna Dixon and others, 'Is the NHS Equitable? A Review of the Evidence" (2003) 11 LSE Health and Social Care Discussion Paper 1.
[20] National Health Service Act (2006) section 1C.
[21] NHS Constitution, 'Staff: Your Responsibility' (2009) <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england> accessed 19 February 2024.
[22] NHS Long Term Plan (2019) < https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf > Chapter 2.

have also, for most part, not been able to fulfil the broader mandate of reducing health inequalities.

While the Health and Care Act 2022 sets a similar objective, having as one of its top priorities to reduce health inequalities[23], it proposes a different approach to decision-making for the allocation of resources in healthcare. This approach departs from previous regulatory approaches and in some respects borrows from principles of *deliberative* regulation. When adopting a deliberative approach, the regulatory process engages with its environment to seek co-created solutions for those directly impacted by decisions.[24] Essentially, regulation becomes 'decentred'.[25] Decision making emerges from collective action, rather than an imposed command by a central regulator.[26] Unlike other regulatory approaches, decisions and recommendations arising in deliberative fora are as crucial as the process through which they come about.[27] Ideally, individuals from different backgrounds and perspectives input their experiences to problem solve and reach reasoned and informed decisions.[28] In theory, all participants should benefit from the process itself, gaining a fuller understanding of the complexities of decision-making and feeling valued for the contribution they make to the regulatory process.[29]

After having provided some context to the reform and summarised the key elements around the objective of reducing health inequalities, in this section we unpack the elements of the Health and Care Act 2022 that reflect some of these *deliberative* principles for the governance of Integrated Care Systems (ICSs) and their Integrated Care Boards (ICBs).

[23] Health and Care Act (2022) section 6.
[24] Prosser (n 9) 9.
[25] Black (n 9); Gunter Teubner, 'How the Law Thinks: Toward a Constructivist Epistemology of Law' 23(5) (1989) Law & Society Review 727.
[26] Id.
[27] Julia Abelson and others, 'Deliberations about deliberative methods: issues in the design and evaluation of public participation processes' (2003) Soc Sci & Med 239.
[28] Id.
[29] Id.

A. Reducing Health Inequalities with Integrated Care Systems

The Health and Care Act 2022 sets an in-depth reform of the organisation of health and social care services. Although not a direct response to the public health crisis, the reform was developed in the context of the SARS-Cov-2 pandemic which brought to the fore the importance of integration and joined up service in healthcare.[30] The reform therefore offers a simplified, and hopefully less fragmented, organisational structure.[31] Under section 14Z27, Clinical Commissioning Groups are abolished and statutory duties for healthcare provision have been bestowed on 42 ICSs across England.[32] ICSs have the overarching mandate to plan, coordinate and commission health and care services, which enables these structures to participate in the strategic planning of resource allocation. The explicit purpose of this new arrangement is to improve health and wellbeing, the quality of services and guarantee the long-term sustainability of the NHS. An express duty is also imposed on NHS England "to reduce inequalities between persons with respect to their ability to access health services" under Title 6 of the Act.[33]

ICS have also been given statutory footing to achieve four goals including improving outcomes in population health and healthcare, and tackling inequalities in outcomes, experience and access.[34] Under section 18 and 26 the Act provides that, in order to achieve this objective, each ICS operates two entities: an ICB overseeing strategic planning and commissioning of services and an Integrated Care Partnership tasked with building collaborations between the NHS and

[30] Department of Health and Social Care, 'Integration and Innovation: Working Together to Improve Health and Social Care for All' (2021) < www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-html-version > 8 accessed 8 July 2024.
[31] Gareth Iacobucci, 'Health and Care Bill: What Changes Do Healthcare Leaders Want to See?' (2021) 374n1806 BMJ 1.
[32] Health and Care Act 2022 s14Z27.
[33] Id. Title 6.
[34] Department of Health and Social Care (n 30) s 2; NHS England, 'Building Strong Integrated Care Systems Everywhere ICS Implementation Guidance on Working With People and Communities' (2021) < www.england.nhs.uk/wp-content/uploads/2021/06/B0661-ics-working-with-people-and-communities.pdf > accessed 8 July 2024.

local authorities to improve local health, care and wellbeing.[35] For the purpose of our analysis, we focus on the ICBs tasked with taking forward ICSs' core allocative activities.

B. Integrated Care Boards and Collaborative Decision-Making

The NHS System Oversight Framework outlines the manifold mandate of ICBs, which ranges from setting system level strategy to commissioning of healthcare services and fostering collaboration with partners to ensure the delivery of policy plans for the community.[36] Each ICB relies on its unitary board constituted of a chair, a chief executive, representatives of NHS boards, the general practice and local authorities[37] to "reduce inequalities between persons with respect to their ability to access health services"[38] and "between patients with respect to the outcomes achieved by them by the provision of health services".[39] The composition of the board's membership is kept under review to address a potential lack in "skills, knowledge and experience"[40]. The governance document also puts emphasis on public involvement in the ICB using a consultation process.[41] This may be establishing a first step to move towards a deeper deliberative model of regulation for these entities.

As part of the ICS structure, ICBs must additionally abide by the ICS guidance accompanying the Health and Care Act 2022 which highlights the importance of people and community involvement to address growing inequalities in health. The document sets out 10 principles to include communities in their work to guarantee that they are consistently listened to and that

[35] Health and Care Act 2022 s18 and 26.
[36] NHS England, 'NHS System Oversight Framework' (2022) < www.england.nhs.uk/wp-content/uploads/2022/06/B1378_NHS-System-Oversight-Framework-22-23_260722.pdf > accessed 8 July 2024.
[37] Anna Charles, 'Integrated Care Systems Explained' (2022) The King's Fund < www.kingsfund.org.uk/insight-and-analysis/long-reads/integrated-care-systems-explained > accessed 8 July 2024.
[38] Health and Care Act 2022 s14Z35.
[39] Id.
[40] Id., s14Z49.
[41] Id., s14Z45.

their lived experiences and the aspirations of people in their local areas are taken into account.[42] Echoing principles of deliberative governance, the guidance crucially suggests that communities and marginalised groups are put at the heart of the decision-making process, through co-production where "family members, carers, organisations and commissioners [can work] together in an equal way, sharing influence, skills and experience to design, deliver and monitor services and projects".[43] It also reinforced that links should be built with deprived and disadvantaged groups for policy to significantly contribute to transformational change where most needed.[44]

Nonetheless, even though the Act introduces changes that directly impact the commissioning of services and indirectly the provision and delivery of healthcare, it does not fully articulate the practicalities around modes of governance and the regulation for the allocation of resources.[45] This may be by design, intentionally leaving the door open for new initiatives to overcome the shortcomings of previous top-down reforms.[46]

Before assessing whether this new approach can in practice create greater equity in accessing healthcare services, it is essential to first look at these historical shortcomings having created and entrenched inequalities in accessing the NHS.

IV. SYSTEMIC FACTORS CONTRIBUTING TO INEQUALITIES IN ACCESSING THE NHS IN ENGLAND

Policy narratives bring forward three factors that have, in our opinion, contributed to inequalities in accessing healthcare in England: (A) inaccurate data and inadequate engagement

[42] NHS England, 'Building Strong Integrated Care Systems Everywhere ICS Implementation Guidance on Working With People and Communities' (2021) < www.england.nhs.uk/wp-content/uploads/2021/06/B0661-ics-working-with-people-and-communities.pdf > accessed 8 July 2024.
[43] Id.
[44] Id.
[45] Id.
[46] NHS England (n 40).

with local populations, (B) a disparity in availability and quality of services, and (C) an excessive culture of performance in the NHS.

Identifying these systemic challenges is an important step in mobilising knowledge to explore an alternative regulatory model for more equitable access to the NHS. As we will show, these factors have straddled across periods of *regulation for social purpose* and *regulation for efficiency and patient choices*, ultimately leading to their failure to reduce access barriers.

A. Inaccurate data and inadequate engagement with local populations

Poor data tracking has, for too long, led to an unequal allocation of resources in England.[47] Deprivation and higher rates of sickness and death have not been sufficiently accounted for, leading to inequities in accessing services. As early as the 1960s, what Hart characterised as an 'inversed care law', started to affect the provision of healthcare services.[48] General practitioners (GPs) facing larger patient lists and secondary care doctors with heavier caseloads, had access to less equipment and support than their counterparts in more affluent areas, making medical care inversely proportional to the population's need. Hart posits that the distribution of medical care in the 1960s was ill adapted to British society's needs and failed to account for social and geographical differences, but explains that this '[could] not be easily proved statistically, because most of the statistics [were] either not available (…) or else they were essentially use-rates."[49]

[47] Office for National Statistics, 'Methods and systems used to collect ethnicity information in health administrative data sources England' (2022) <www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/articles/methodsandsystemsusedtocollectethnicityinformationinhealthadministrativedatasourcesengland2022/2023-01-16> accessed 8 July 2024; Robin Haynes and Susan Gale, 'Deprivation and poor health in rural areas: inequalities hidden by averages' (2000) 6 (4) Health & Place 275.
[48] Hart (n 2) 409.
[49] Id.

In addition, a lack of effective and substantial engagement with local populations through communication or meaningful partnership between service users, healthcare providers, and authorities for the design of healthcare policy led some communities to face challenges accessing formal healthcare settings.[50] Their voices not being heard (or not being consulted in the first place) when taking decisions over resource allocation resulted in, as one of the authors has argued elsewhere, policies not fit for purpose in terms of addressing the needs of disadvantaged and marginalised communities.[51] This may be because the engagement of communities in healthcare decision-making has been in many instances informal and ad hoc.[52]

We can point to some examples to this effect with initiatives as early as the 1970s, with the Community Health Councils (CHCs) established to give a voice to patients and the wider public on policies having a substantial impact on the development of health services.[53] Although the CHCs' purpose was to "represent the interests in the health service of the public in its district"[54], the law did not outline how they would do so in practice.[55] As a result, their influence varied across the country and was often limited to protest without compelling concrete actions.[56] Even though patient voice had entered the resource allocation discussion, the effect of CHCs was sparse.

Similarly, although not directly engaging public voices in policy, the GP fundholding entities created under the NHS Community and Act 1990 demonstrated how poor data gathering could

[50] Jennifer Crane, 'Why the history of public consultation matters for contemporary health policy' (2018) 42(1) Endeavour 9.
[51] Sabrina Germain and Adrienne Yong, 'COVID-19 Highlighting Inequalities in Access to Healthcare in England; a Case Study of Ethnic Minority and Migrant Women' Fem. Legal Studies (2020) 28(2) 301.
[52] Craig Mitton and others, 'Public Participation in Health Care Priority Setting: A Scoping Review' (2009) 91 Health Policy 219.
[53] National Health Service Reorganisation Act 1973 c. 32, 9.
[54] Id. 9 (3).
[55] Crane, (n 50).
[56] Rudolf Klein, *The New Politics of the NHS: From Creation to Reinvention* (Radcliff 2013) chp 4.

result in disparities in accessing healthcare services.[57] GP fundholding entities were assigned a budget to purchase care for their patients from providers (hospital and community groups). However, data tracking skewed the allocation process, favouring practices with better recording systems because funds were distributed in line with records of patient usage.[58] This meant that the GP surgeries that were able to record greater activity secured higher budgets than those with defective recording systems, even if the latter had greater needs for care. Regional authorities were also favourably biased towards fundholding practices and offered them a more generous allocation of funds.[59] This inevitably led to disparities between fundholding and non-fundholding practices, ultimately favouring more affluent communities.[60]

Much in the same way, introduced under the New Labour government in 1999, Primary Care Groups (PCGs) and their later iteration the Primary Care Trusts (PCTs), were designed to reduce disparity through the management of hospital resources.[61] Although adjustments for deprivation were made to PCT's allocation formula, structural inequalities endured.[62] The General Medical Practice (GMS) contract governing GPs activities also contributed to the issue. While the contract was designed to account for patients' diverse needs, the GMS's Carr-Hill formula perpetuated disparities by favouring elderly patients. The formula used patient age as a weighting, which made it a significant factor for determining the funds allocated to each GP surgery.[63] This was most problematic in areas of high deprivation where structural

[57] Chris Ham, 'Governing the Health and Care System in England: Creating Conditions for Success' (2022) NHS Confederation <www.nhsconfed.org/publications/governing-health-and-care-system-england> access 8 July 2024.
[58] Angela Coulter, 'Evaluating General Practice Fundholding in the United Kingdom' (1995) 5(4) European Journal of Public Health 233.
[59] Jennifer Dixon, 'Can There be Fair Funding for Fundholding Practices?' (1994) 308 BMJ 772.
[60] Id.
[61] Ham (n 57) 50.
[62] Martin Wenzl and Elias Mossialos, 'Achieving Equity in Health Service Commissioning', in Mark Exworthy and others (eds) *Dismantling the NHS?* (BUP 2016).
[63] Jake Beech and Beccy Baird, 'GP Funding and Contract Explained' The King's Fund (2020) <www.kingsfund.org.uk/insight-and-analysis/long-reads/gp-funding-and-contracts-explained> accessed 8 July 2024.

inequalities had significantly reduced patients' life expectancy and meant that GP practices catering to younger and sicker marginalised groups remained critically underfunded.[64]

Efforts to gather the population's input in health policy decision making have also fallen short of creating effective feedback and co-creation mechanisms for the planning, commissioning, and provision of healthcare services. While intended to increase accountability and involve local stakeholders such as patient representatives and staff in decision-making, the establishment of Foundation Trusts (FT) in 2002 failed to empower community members.[65] Based on a loose model of 'social ownership', FTs were designed with a two-tier governance structure, where a board of governors comprising local stakeholders with patient representatives and members of staff were supposed to give prominence to their interests and needs.[66] In reality, governors had little control over the management of the organisation and no real influence on the standards and types of services delivered by the FT.[67] Members and citizens only had a consultative role, and because devised accountability mechanisms were weak, the FT board of directors were under little obligation to take into account the governors' opinion. Consequently, members and governors in many FTs felt a sense of powerlessness and had limited influence over decisions and the future of their organisation.[68]

B. Disparity in Availability and Quality of Services

A second factor affecting equal access to healthcare services is rooted in other issues affecting the NHS, sometimes because of the complete unavailability of healthcare services or the

[64] Nick Bostock, 'GP Funding Formula Perpetuates Inequalities, MPs Told' (2022) *GP Online* < www.gponline.com/gp-funding-formula-perpetuates-inequality-mps-told/article/1749937 > accessed 8 July 2024.
[65] Id.
[66] John S F Wright and others, 'The New Governance Arrangements for NHS Foundation Trust Hospitals: Reframing Governors as Meta-Regulators' (2012) 90(2) Pub Admin 351.
[67] Id.
[68] Richard Lewis and Lisa Hinton, 'Citizen and Staff Involvement in Health Service Decision-Making: Have National Health Service Foundation Trusts in England Given Stakeholders a Louder Voice?' (2008) 13(1) J. Health Serv Res Policy.19.

varying standards in delivery across communities in England. Phenomena such as the 'postcode lottery' of services, with some areas receiving NHS funding for a drug or treatment while others do not, persistently affect patient access to healthcare services.[69] Despite efforts to align resource allocation with social and geographical differences, fragmentation and variation in coverage have become more acute over time.[70] Looking back, some of these issues can be traced as far as the inception of the NHS.

The post-war fragmentation of healthcare services and the health inequalities in the population worked against Bevan's initial plan to eradicate ill health with a universal healthcare system.[71] Historical policy choices, such as the nationalisation of hospital services and the training of specialists and ancillary staff in the Poor Law hospitals after 1948, helped hospitals improve the quality and delivery of services, but resulted in unanticipated growing expenditures. As a consequence, from its creation, the NHS has had to compete with other public services for a greater share of public funds.[72] During that time community medicine was also organised independently from health services and remained under the control of local authorities which resulted in a lack of coordination between healthcare services and community medicine and an uneven provision of services.[73]

In the following decades and particularly in the 1980s to the 1990s, the ever-increasing expenditure and the opaque allocation of funds in healthcare became even more problematic. In 1999, the National Institute for Clinical Excellence (NICE) was created with the purpose to help reduce the variation in the availability and quality of treatments using a more objective

[69] Jill Russell and others, 'Addressing the 'Postcode Lottery' in Local Resource Allocation Decisions: a Framework for Commissioning Groups' (2013) 106(4) J R Soc Med 120.
[70] Justine Karpusheff, 'Who is more likely to lose in the postcode lottery of health?' (2023) The Health Foundation <www.health.org.uk/news-and-comment/blogs/who-is-more-likely-to-lose-in-the-postcode-lottery-of-health> accessed 8 July 2024.
[71] Rudolf Klein, *The New Politics of the NHS: From Creation to Reinvention* (Radcliff 2013) chp 4.
[72] Paul Higgs and Ian Rees Jones, 'Finite Resources and Infinite Demand' in Graham Scambler (ed) *Habermas, Critical Theory and Health* (Routledge 2001).
[73] Charles Webster, *The National Health Service: A Political History* (OUP 2002).

benchmark (quality adjusted life years) to appraise new treatments and technologies offered on the NHS. Nonetheless, discrepancies in accessing NHS funded healthcare services remain, and NICE has been the object of criticism pertaining to the assessment criteria used to prioritise funding.[74]

More recently, as part of the Health and Social Care Act 2012 mandate to take on elements contributing to disparity in the availability and quality of services,[75] greater autonomy was granted to GPs to commission local services with significant discretion.[76] Clinical Commissioning Groups (CCGs) - essentially GP budget holding consortia - were given full control over the range of primary and secondary care services they wished to provide in their area. However, during the implementation phase, disparities between CCGs emerged.[77] CCGs had limited capacity to identify inequities because of a lack of robust data to support their commissioning process. They also did not embed community engagement in their decision-making processes leading to variations in access to healthcare services.[78]

C. Excessive Culture of Performance

In parallel to the above factors, since the 1950s, the monitoring of healthcare policies and vertical accountability arrangements (hierarchical and centralised control for the assessment of programmes' efficiency) have been mostly focused on performance management and value for money, rather than patient outcomes and the reduction of inequalities in accessing healthcare

[74] Keith Syrett, 'Nice Work? Rationing, Review and the 'Legitimacy Problem' in the New NHS' (2002) 10 Medical Law Review 1; Rudolf Klein, 'Dimensions of rationing: who should do what?' (1993) BMJ 307.
[75] Health and Social Care 2012: Fact Sheets, 'The case for change- the Health and Social Care Act 2012' (2012) <https://assets.publishing.service.gov.uk/media/5a7b0c22e5274a319e77ca2a/A2.-Factsheet-Case-for-change-240412.pdf> accessed 8 July 2024.
[76] ACL Davies, 'This Time, it's for Real: the Health and Social Care Act 2012' (2013) 76(3) MLR 429.
[77] Sheena Asthana and Alex Gibson, 'The National Health Service (NHS) in 'crisis': the role played by a shift from horizontal to vertical principles of equity' (2018) 15(1) Health Economics, Policy and Law 1.
[78] Martin Wenzl and others, 'Commissioning for equity in the NHS: the rhetoric and practice' (2015) 115 (1) British Medical Bulletin 5.

services.[79] This pronounced focus on performance has been influenced by the private sector, with cost reduction seen as an indicator of good performance. Non-economic elements offering added value to marginalised communities and impacting public service outcomes have, unfortunately, been thoroughly overlooked.[80] A striking example of this is the introduction of the New Public Management approach by Margaret Thatcher's 1980s Conservative governments, with economic rationalism and private sector-inspired standards of performance introduced into healthcare.[81] The aim of these policies was to achieve more with the same budgets and address patient needs and the long waiting lists that had arisen from a lack of accountability in the NHS and an inefficient allocation of resources.[82] Performance indicators, financial targets and new regulatory mechanisms were thus introduced to maximise gains and deal with variations in quality. However, especially the backlash from medical professionals, disgruntled with their new managerial and budgeting responsibilities, undermined the system of performance valuation.[83]

Similarly, New Labour policies in the 2000s continued to prioritise an excessive culture of performance through a 'target and terror' approach. This emphasised financially-oriented results, cost containment and efficiency gains.[84] Quality controls, along with financial audits to hold accountable healthcare providers, were introduced and became more prominent. Hospitals were indirectly incentivised to 'game the system' and to put 'targets before care', as the rating directly impacted the retention of their health managers.[85] The culture of performance reinforced by star ratings and centralised micromanagement limited providers' autonomy and

[79] Ewan Ferlie, 'Exploring 30 years of UK Public Services Management Reform-the Case of Health Care' (2017) 30 (6-7) International Journal of Public Sector Management 615.
[80] Stephen P Osborne and others, 'Beyond co-production: Value Creation and Public Services' (2021) 99 Pub Admin 641.
[81] Chris Ham, *Health Policy in Britain* (Palgrave Macmillan 2009).
[82] Department of Health and Social Services, 'NHS Management Inquiry' (Griffith Report) HMSO (1983).
[83] Geoffrey Rivett, *From Cradle to Grave: Fifty Years of the NHS* (King's Fund 1998).
[84] Gwyn Bevan and Christopher Hood, 'What's measured in What Matters; Targets and Gaming in the English Public Health Care System' (2006) 84(3) Pub Admin 517.
[85] Id.

strategic decision-making capacity as they prioritised meeting targets rather than improving services.[86]

Even the subsequent introduction of indicators aiming to capture quality of care, such as mortality and readmission rates and patient reported outcome measures, have failed to properly cater to the patient perspective of the care offered.[87] Patient experience, when sought, has not subsequently been used as a systematic quality improvement tool.[88] Overall, the pervasive (in many ways distorted) culture of performance in healthcare policy so far, has led to risk aversion, limited community engagement, and challenges in effectively addressing patient needs.

The policy analysis presented in this section demonstrates that the inequities and barriers in accessing the NHS stem from long-standing systemic factors that both the *regulation for social purpose* or a *regulation for efficiency and patient choice* have failed to adequately address. With this understanding, we are driven to explore deliberative regulation's potential to address more significantly these systemic challenges affecting marginalised groups[89] and further the societal ends of equity in accessing the NHS.

V. DELIBERATIVE REGULATION TO ACHIEVE GREATER EQUITY IN ACCESSING THE NHS

A deliberative approach to regulation could be harnessed to bring forward the complex experiences of marginalised groups for the strategic planning, coordination and commissioning

[86] Laurence Ferry and Simona Scarparo, 'An era of Governance Through Performance Management New Labour's National Health Service from 1997 to 2010' (2015) 2(3) Accounting History Review 219.
[87] See for example, John P Browne and others, 'Using Patient-reported Outcomes Measures to Improve Health Care: Time for a New Approach' Med Care (2017).
[88] Kendall Jamieson Gilmore and others, 'The use of Patient Reported Experience Measures in Health Systems: A Systematic Narrative Review' Health Policy (2023) 128 1.
[89] Sabrina Germain and others, 'Key Areas for Targeting Innovations to Tackle Health Inequalities in the English NHS' UCLPartners Report (2021).

of healthcare services, and to help dissipate barriers in accessing the NHS. As explained earlier, some of the marginalised groups' needs continue to be unaddressed, in part because of their limited involvement in allocative decisions.[90] We explore deliberative regulatory theory as a critical approach to rethink resource allocation and to better involve marginalised groups in the design of healthcare policies. First, we unpack the theory's main principles and apply them to resource allocation decision making. We then present some of the limitations of this approach in the context of healthcare.

Although abundant literature has already explored the potential of deliberative approaches in healthcare policy creation[91], few studies have looked at frameworks that evaluate propositions for public engagement in resource allocation or healthcare priority setting.[92] Bearing this in mind, in the last part of this section, we outline a framework to assess current and future law and policy propositions to gauge their potential to create greater equity in healthcare using deliberative methods.

A. The Theory of Deliberative Regulation

The essence of deliberative regulation theory rests in Habermas' work on communicative ethics which posits that fair procedures are essential for appraising the validity of normative claims.[93] This is why deliberative regulation goes beyond public consultation. At least in theory, it involves in-depth two-way interactions among all participants and mandates an adequate space for self-regulation to emerge.[94] Deliberation also provides a more refined process than a vote

[90] See also, Claudia de Freitas and Graham Martin, 'Inclusive Public Participation in Health: Policy, Practice and Theoretical Contributions to Promote the Involvement of Marginalised Groups in Healthcare' (2015) 135 Soc Sci & Medicine 31.
[91] World Health Organisation, 'Ninth Futures Forum on Health Systems Governance and Public Participation' WHO (2006) < https://iris.who.int/handle/10665/107357> accessed 8 July 2024; Anna Coote, 'Public Participation in Decisions about Health Care' (2007) Critical Public Health 36.
[92] Craig Mitton and others, 'Public Participation in Health Care Priority Setting: A Scoping Review' (2009) 91 Health Policy 219.
[93] Jurgen Habermas, *Between Fact and Norms* (MIT Press, 1998).
[94] Abelson (n 27).

on propositions. In the deliberative process, preferences and alternative views are to be argued and shape the normative outcome.[95]

When theorising deliberative regulation, Prosser explains that participants need to be given the autonomy to deliberate and reach a decision. This requires an 'ideal speech situation', a forum in which deliberations take place to allow for consultation, accountability, openness and transparency among participants.[96] All participants' input should also be equally valued and considered regardless of their level of expertise or communication skills.[97] Expert knowledge in a specific area will not qualify a participant in interpreting the needs of others.[98]

In a context outside of healthcare, Gehring and Kerler provide an interesting and more concrete roadmap to proceed with deliberative regulation. They suggest a two-stage approach.[99] In stage 1, participants agree on decision criteria. These broad principles and values are determined prior to the discussions in stage 2. The propositions and positions put forward during the subsequent argumentative phase (stage 2) are evaluated against the broad principles/criteria to ensure decisions are made consistently and fairly. All participants should have the opportunity to provide input on the criteria before becoming aware of their case-specific preferences. In stage 2, participants argue allocative propositions. For this, they must support their position by highlighting how these propositions best fit the stage 1 commonly agreed decision criteria. A collective decision should emerge from these argumentative discussions.[100]

[95] Katharina Kieslich and others 'Accounting for technical, ethical, and political factors in priority setting' (2016) 2 Health Systems & Reform 51.
[96] Prosser (n 9) 17.
[97] Jurgen Habermas, 'Discourse Ethics: Notes on a Program of Philosophical Justification' in S. Benhabib and F. Dallmayr (eds), *The Communicative Ethics Controversy* (1990).
[98] Jones (n 15).
[99] Thomas Gehring and Michael Kerler, 'Institutional Stimulation of Deliberative Decision-Making: Division of Labour, Deliberative Legitimacy and Technical Regulation in the European Single Market' (2008) 46 (5) JCMS 1001.
[100] Id.

Habermas also theorises that the decisions made in deliberative fora emerge from public reason, a rationale deemed acceptable to all participants.[101] Participants are encouraged to argue opposite views and persuade one another in order to reach a decision.[102] Black points out that the deliberative normative space is a polyarchy rather than a democracy with multiple, rather than one, sites of power.[103] This highlights a shift from the traditional regulator's command to achieve a specific goal, to more indirect strategies designed by regulatory subjects to achieve potentially similar aims.[104] With a deliberative approach, regulatory subjects gain a substantial degree of autonomy to lead on the development of an internal mode of regulation, taking over some of the regulator's discretionary power.[105] The rationale here is that regulatory subjects can more accurately inform allocative decisions because of the knowledge that they hold of their own challenges and lived experiences. Regulatory subjects are also more likely to comply with the rule that they have designed.[106]

External responsiveness is yet another crucial element of deliberative regulation. Participants have to think reflexively about their dual role as regulator and regulatory subject.[107] Along with decision-making, accountability mechanisms are developed, and participants could be required to engage in the monitoring of activities and explain how their decisions have to be implemented.[108] In some aspects this increases the legitimacy of the final decisions and helps support their implementation.[109] Indeed, Daniels and Sabin argue that authority tends to be accepted as legitimate if it abides a procedure, and a rule is based on rationales that are publicly

[101] Jurgen Habermas, 'Three Normative Model of Democracy' in Seyla Benhabib and Fred R Dallmayr (eds), *Democracy and Difference: Contesting the Boundaries of the Political* (MIT Press 1996).
[102] See John S Dryzek, *Deliberative democracy and beyond* (OUP, 2000).
[103] Black (a) (n 13).
[104] Chris Degeling and others, 'Which public and why deliberate? A Scoping Review of Public Health and Health Policy Research' (2015) 131 Soc Science & Med 114.
[105] Gunter Teubner, 'Substantive and Reflexive Elements in Modern Law' (1983) 17 Law. Soc. Rev. 239; Black (a) (n 13).
[106] Coglianese (n 14) 152.
[107] Id. 147-148.
[108] Prosser (n 9) 17.
[109] Abelson (n 27).

available and agreed up by 'fair-minded people'.[110] With 'fair-minded people', they mean individuals willing to engage in collective decisions by following a pre-agreed process. As a result, the rule created becomes legitimate because the conditions for deliberation have been respected. In the same way, Black contends that the process of policy and law formation through deliberation becomes both a technique and a legitimising base.[111]

B. Limitation of a deliberative approach to regulation for the allocation of healthcare resources

Although the deliberative approach (and the ideal speech situation it requires) should be taken as a normative guide rather than a practical roadmap[112], we need to understand the limitations it may bring in practice in the realm of healthcare and account for them in our evaluation of law and policy propositions.[113]

Three practical challenges immediately come to mind. First there is potential for (1) imbalanced power dynamics and vested interests to affect and disrupt the deliberative process. This is because participants may bring in bias or subjective information into the deliberative forum. The public might also be (2) reluctant to engage with healthcare rationing which may lead to a narrower representation in deliberative fora. Finally, the dynamics around (3) shared accountability may also be difficult to manage. We discuss each of these issues in turn.

1. Imbalanced power dynamics and vested interests

[110] Daniels (n 10).
[111] Black (a) (n 13).
[112] Jones (n 15).
[113] Abelson (n 27).

To 'adequately' set priorities or to allocate resources in healthcare, the two-stage deliberative process needs not to be distorted by power dynamics.[114] Individuals and groups of stakeholders must refrain from dominating with their preferences or opinions.[115] Habermas' communicative theory is unhelpful in solving this practical problem as it ignores the challenge by establishing that 'ideal speech situations' will automatically exclude these dynamics through dialogue.[116] In reality, as Bourdieu explains, the institutional context for decision-making is actually irrelevant since power resides within words.[117] Also, by nature, healthcare decisions are value-laden and the product of power interests.[118]

For some, their scientific expertise gives them the power to justify their vested academic or professional interests.[119] These perspectives may be less transparent than those of patient groups because medical knowledge legitimises their perspectives. Conflicts of interest among lay members can also occur since all participants have the opportunity to steer decisions towards their preferred outcomes, and it is often challenging for lay members, particularly from patient groups, to make the distinction between private and public involvement.[120] Private involvement in decisions making implies that participants advocate or lobby others for their own medical treatment or experiences, whereas with public involvement participant's input is taken as representative of the wider community's perspective on decisions.[121]

These conflicting motivations and power relations can be addressed by introducing substantive values in the decision criteria in stage 1 of the deliberative process.[122] When presented with

[114] Lars Sandman and others, 'Rethinking patient involvement in healthcare priority setting' Bioethics (2019) 34(4) 403.
[115] Higgs (n 72).
[116] Russell Keat, *The Politic of Social Theory* (Blackwell, 1981).
[117] Pierre Bourdieu, *Language and Symbolic Power* (CUP, 1991).
[118] Abelson (n 27).
[119] Higgs (n 72).
[120] Sandman (n 114).
[121] Id.
[122] Sarah Clark and Albert Weale, 'Social values in health priority setting: a conceptual Framework' (2012) 26 Journal of Health Organization and Management 293.

'technical' choices that involve a targeted response, for example opting to provide a new medicine or technology on the NHS, these criteria are most helpful.[123] But they may not be as helpful with more complex 'political' decisions on health priorities or for the appraisal of competing programmes (for example whether to finance a programme for the management of chronic diseases *vs.* a programme to support children and young adults' mental health).[124] Black only offers a partial solution to these issues suggesting that mediator or 'translator' operates within the deliberative forum, to rebalance dynamics impacted by the distorting effects of power and to facilitate, if need be, dispute resolution.[125]

Resources should also be mobilised to effectively realise a deliberative approach to regulation in healthcare. Technical knowledge and information asymmetry need to be resolved by upskilling participants from marginalised communities in order for them to engage with the process on equal footing with NHS civil servants and medical professionals.[126] These participants need to have the ability to weigh in evidence, discuss and debate potential options for a genuinely and mutually agreed decision to be reached.[127]

2. 'Reluctant rationers' and narrow representation

Although, as discussed above, imbalance in power dynamics and conflicts of interest can be detrimental to the deliberative process, it is unrealistic to expect participants to remain completely neutral when representing their communities' interest in this decision-making

[123] Horst WJ Rittel and Melvin M Webber, 'Dilemmas in a general theory of planning' (1973) 4 (2) Pol. Sci. 155.
[124] Iestyn Williams, 'Receptive rationing: reflections and suggestions for priority setters in health care' (2015) 29(6) Journal of health Organisation and Management 701.
[125] Black (a) (n 13).
[126] Len Doyal, 'Need for moral audit in evaluating quality in health care' (1992) 1 Quality in Health Care 178.
[127] Abelson (n 27).

forum.[128] Research also shows that the public wants to get involved with health policy when their interests are directly affected by the decisions.[129]

This is not to say that the public eagerly engages with resource allocation or rationing decisions. To the contrary, priority setting and the allocation of scare resource always involves balancing competing needs[130] and decisions carry considerable emotive and political significance which weighs heavily on all decision makers.[131] Lomas[132] and Syrett[133] both talk about 'reluctant rationers', citizens that believe they do not possess the ability to significantly contribute to decisions for the allocation of healthcare resources. Farmakas and colleagues go further in explaining that the public is often reluctant to engage with the process because they do not want to carry the responsibility of these decisions.[134] This significantly limits the deliberative approach in practice. Marginalised groups are likely to also want to avoid having to defend or to be held accountable for complex, controversial, and consequential decisions impacting their community.[135] This may reduce the pool of participants and narrow down representation in deliberative fora.

As a solution Parkinson proposes that representation in deliberative forums follow some basic principles.[136] Affected stakeholders should be granted the freedom to decide in which instance they want to be represented, leaving the deliberative process open ended. Parkinson also

[128] Sigurd Lauridsen and Kasper Lippert-Rasmussen, 'Legitimate allocation of public the justification healthcare: Beyond accountability for reasonableness' (2009) 2 Public Health Ethics 59.
[129] Abelson (n 27).
[130] Sandman (n 114).
[131] Williams (n 124).
[132] Jonathan Lomas, 'Reluctant Rationers: public Input into Health Care Priorities' (1997) 103 (2) Journal of Health Services Research and Policy 107.
[133] Keith Syrett, *Law, Legitimacy and the Rationing of Health Care: A Contextual and Comparative Perspective* (CUP, 2007).
[134] Antonis Farmakas and others, 'Rationing Resources in Health by Involving the Public in Priority Setting' 19 (2016) Value in Health.
[135] Sandman (n 114).
[136] John Parkinson, 'Legitimacy problems in deliberative democracy' (2003) 52 Political Studies 180.

proposes that communities elect representatives and that marginalised groups be involved regardless of their size.[137]

3. Challenges around shared accountability

Trust and collaboration in a deliberative forum may foster substantial horizontal accountability (stakeholders holding each other responsible).[138] The regulator may retain some oversight on the implementation of the regulatory subject's decisions building an added layer of accountability.[139] The collective nature of this regulatory approach, however, makes constructing governance mechanisms more challenging because individuals cannot be held responsible for specific decisions. Looking at this differently, collective accountability also allows diffuse blame for difficult or unpopular rationing decisions among participants.[140]

Overall, the democratisation of the priority-setting and the allocation process should have participants assume greater responsibility for their decisions.[141] It is important that their participation is not limited to a tokenistic consultation, but to an in-depth two-way process as previously laid out.

C. Evaluative Framework

Our novel evaluative framework is grounded in the theory of deliberative regulation while also accounting for the limitations outlined above. The framework offers a critical reading grid to appraise law and policy choices and determine whether they provide solutions to correct the failure of previous regulatory approaches by adopting a deliberative approach. Each

[137] Karen M Facey, 'Developing the mosaic of patient participation in HTA' in Karen Facey and others, *Patient involvement in health technology assessment* (Springer 2017) 51–65.
[138] Mark Bovens, 'Analysing and Assessing Accountability a Conceptual Framework' (2007) 13 European Law Journal 447.
[139] Id.
[140] Abelson (n 27).
[141] Jones (n 15).

framework's dimensions speaks to one of the systemic challenges highlighted in the second part of our analysis. The first dimension assesses the (1) degree and quality of participation of marginalised groups in resource allocation decision-making to determine whether issues of inaccurate data and inadequate engagement with the local population are more adequately addressed. The second dimension on the (2) degree of involvement of marginalised groups in priority-setting, provides theory-grounded criteria to critically appraise initiatives addressing disparity in availability and quality of services. The third and final dimension assesses the (3) degree of involvement in the design of accountability mechanisms of marginalised groups to understand whether the assessed proposition signals a shift away from an excessive culture of performance in healthcare.

1. Degree and quality of participation

This framework dimension examines the mechanisms mobilised to reach out and engage regulatory subjects and assesses whether an inclusive forum has been put in place to allow marginalised groups to meaningfully deliberate on allocative decisions.

Deliberative regulation is a helpful mechanism to gather information, effectively mobilise knowledge and regulate more intentionally the allocation of resources.[142] As a form of decentralised regulation it operates on the premise that participants uniquely have knowledge that is crucial for solving a social problem.[143] Throughout this process, two-way communication is therefore essential to generate the data that captures marginalised groups' lived experiences in accessing healthcare services.

[142] Anne Mette Mooler, 'Deliberation and Deliberative Organisational Routines in Frontline Decision-Making' (2021) 31(3) J Pub Admin Research and Th 471.
[143] Black (n 9).

For this, deliberative participation by members of marginalised groups needs to go beyond a consultation or a 'listening exercise'. Throughout the decision-making process, on par with NHS stakeholders, communities need to *engage* as equal partners to exercise a substantial and active role in the management and governance of resource allocation. It is essential for the voices of these communities to be placed at the heart of deliberations, even where those voices are telling stories that are not reflected in the data.[144] With this participatory approach, marginalised groups' unique needs and perspectives will be centred and potentially brought into the policy-making arena. By sharing their lived experiences, these groups have an opportunity to influence decision making.

However, systems do not operate in a vacuum, relationships shape interactions and the operation of the NHS structures. Establishing trust among decision makers is central to working toward reducing health inequalities collaboratively.[145] The government and the NHS as an organisation should go out to these communities and offer an inclusive and suitable forum to support their involvement in the allocation process. The onus cannot be on marginalised communities who already feel the detrimental effect of policies that have ignored their needs. Some adaptation and evolving relationships to foster trust between community participants, clinical experts and policy makers may be required.

2. Degree of involvement in priority setting

This framework dimension evaluates the extent to which the implementation of a law or policy is the product of in-depth interactions among the participants. It also determines whether a deliberative approach was intentionally adopted to achieve this goal.

[144] Clair Thorstensen-Woll and others, 'Understanding Integration: How to listen to and Learn From People and Communities' The King's Fund (2021) <https://assets.kingsfund.org.uk/f/256914/x/6cb94b878d/understanding_integration_guide_2021.pdf > accessed 8 July 2024.
[145] Lucy Gilson, 'Trust and the development of health care as social institution' (2003) 56 Soc Sci & Med 1453.

Deliberative regulation provides an opportunity to take decisions based on marginalised groups' lived experiences. Through the deliberative processes, groups and communities' needs, and the impact that wider determinants of health has on them, can be accounted for in allocative decisions. For this, service users and communities need to feed into the core values and principles that shape the decision criteria in the initial phase of the deliberative process. As they often are the closest to marginalised communities, primary care providers, the community and voluntary sector should also be mobilised. Co-created solutions and sustainable changes are likely to emerge and, in the long term, benefit the population as a whole.[146]

In the second stage of the deliberative process, allocative decisions need to be appraised against the agreed criteria, for instance, (1) the potential to enhance equity, (2) the degree of responsiveness to community's needs, or (3) the clinical effectiveness of an intervention, etc. These criteria are essential to support consistent and legitimate decisions alleviating participants' discretionary preferences.[147] At this stage, stakeholders from marginalised groups, together with other participants (clinical experts, civil servants, policy experts), can deliberate and point to the rationale that underpin the allocative propositions and interventions they support.[148] In depth discursive practices during this process are essential to bringing about transformational change.[149]

3. Degree of involvement in the design of accountability mechanisms

This framework dimension assesses the extent to which marginalised groups have been able to use a deliberative approach to develop accountability mechanisms, and whether they are being held accountable for the decisions they made while engaging in the deliberative process.

[146] James Booth, 'Empowering Disadvantaged Communities in the UK: Missing the Potential of Co-Production' 49 (2) (2019) Social Change 276.
[147] Mooler (n 142).
[148] Id.
[149] Jones (n 15).

Commissioning and other allocative decisions need to promote community interests and build strong health responses to address structural issues leading to inequality in access. Therefore, once priorities are set and decisions are made, the deliberative regulatory process should support setting boundaries for implementation and devise accountability mechanisms. A deliberative approach can be used to this end and to foster collective responsibility.[150] In this context, the decentralised approach of deliberative regulation is likely to encourage a shift from a culture of performance to one of greater trust between the NHS and its service users. All participants, including those from marginalised communities, need to be supported in designing mechanisms to hold themselves accountable to the decisions they have co-produced.[151] Also, since patient outcomes correlate with marginalised groups' willingness to engage with formal services, patient experience and patient-centred outcomes are likely to become more of a focal point than regional targets and performance benchmarks.[152]

Even though the NHS traditional mode of vertical accountability has shown its limitations, input from 'traditional' regulators continues to be relevant. A hybrid approach that combines mutual accountability and an external system of governance, allowing a regulator to retain a level of oversight on implementation, can be developed. With complementary modes of accountability, the government and its agencies, for example the Care Quality Commission, could remain involved in auditing the enforcement of decisions relating to the allocation of healthcare resources. Clinical staff, providers, NHS civil servants and members of marginalised groups may be inclined to focus on local solutions which could also make it more manageable for them to hold each other accountable.[153]

[150] Michael West and others, 'Developing collective leadership for healthcare' *Kings Fund* (2014) < https://assets.kingsfund.org.uk/f/256914/x/9406fe95d0/developing_collective_leadership_2014.pdf> accessed 8 July 2024.
[151] Coglianese (n 14) 151.
[152] Ham (n 57).
[153] Chris Ham, 'Integrated Care Systems Must Be Agile and Avoid Becoming Ensnared in Bureaucracy' (2022) 78:o1626 BMJ 1.

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[insert table here]

We contend that by using a deliberative regulatory approach the needs of the local community can be better addressed through the decisions of the groups most impacted by resource allocation. More informed decisions may emerge from more accurate data around marginalised groups' needs, as well as a shift from an excessive culture of performance to a more service user focused approach.

We now turn to a case study, using our evaluative framework we examine some of the law and policy interventions resulting from the enactment of the Health and Care Act 2022.

VI. EVALUATING LAW AND POLICY CHOICES: FRIMLEY'S INTEGRATED CARE SYSTEM

In this section, we empirically appraise the allocative mechanisms used by ICSs when setting strategy and taking decisions to allocate resources for their local population. A case study helps us consider the extent to which the ICS model provides an adequate terrain for deliberative regulation to develop and better tackle inequities in access to the NHS.

The Frimley ICS came together in 2017 and formally acquired its status as a statutory body in 2022 as per the Health and Care Act 2022. The Frimley ICS commissions and delivers health and social care services for 810,000 people with the support of 72 GP practices.[154] Although located in the affluent Southeast England region, the ICS's ICB covers a socio-economically, racially and ethnically diverse population with noticeable pockets of deprivation, particularly in the local area of Slough where 69% of the population is underserved, 150 languages are spoken, and close to 15% of children live in low-income families.[155] The ICB explicitly presents itself as a structure that "will work collaboratively with partner organisations including

[154] NHS Frimley, 'NHS Frimley Integrated Care Board Governance Handbook v 2.1' (2023) < www.frimley.icb.nhs.uk/policies-and-documents/how-we-make-decisions/1541-frimley-icb-governance-handbook/file > 3 accessed 8 July 2024.
[155] Kumar (n 16).

the voluntary, community and social enterprise sector, people and communities across the Frimley Health and Care Integrated Care System"[156]. It also outlines in its strategic Joint Forward Plan the objective of reducing health inequalities.[157]

This ICB, therefore, offers an ideal case study to assess whether the reform has brought in a deliberative approach for the allocation of healthcare resources to better cater to its diverse population's needs. Because its existence predates the reforms introduced by the 2022 Act, this ICS is more likely to have had the time to develop mechanisms that meaningfully include marginalised groups in allocative decision-making processes.

For our analysis, we focus on the key documents that govern the organisation and operations of Frimley ICB to understand the extent to which it has adopted a deliberative approach to resource allocation. We first examine the ICB's Constitution and Governance Handbook that articulates the structure of the board and its duties. This helps us to understand the workings of the Board and its practices. We then present the themes that emerged from our analysis of the Board Meetings' minutes, covering the period from July 2022 to January 2024. This evaluation was guided by the questions outlined in our evaluative framework (see Table 1).

A. Frimley ICB's Constitution and Governance Framework

The Frimley ICB's Constitution outlines the composition of the Board, its structure, procedures and arrangements for public involvement in the performance of the Board's duties. In accordance with the Health and Care Act 2022, the Constitution provides for an independent chair of the Board, a chief executive, eight ordinary members and two non-executive members. The ordinary members of the Board are expected to bring in expertise on primary and

[156] Frimley ICS, 'About Us' < https://www.frimley.icb.nhs.uk/about-us> accessed 8 October 2024.
[157] Frimley ICS, 'NHS Joint Forward Plan' (2023) < https://www.frimley.icb.nhs.uk/policies-and-documents/governing-body-meeting-papers/nhs-frimley/2023-1/june/1701-5-1-joint-forward-plan-summary-version/file > accessed 8 October 2024.

secondary care services and on the social care services available in the area.[158] Any individual can be appointed as a non-executive member by the Board for a period of three years.[159]

Members of the community are not specifically called on to occupy these roles, however, the presence of non-executive members on the Board is envisioned as providing a liaison between the Board and the community according to ICS Implementation Guidance on Working with People and Communities.[160] They are also to provide an independent perspective on to the Board, helping ensure that it fulfils its statutory duties, particularly with regards to public and patient participation.[161] However, marginalised groups are in reality less likely to volunteer in such roles because of circumstances like precarious employment, limited skills, caring responsibilities, or challenges around mobility and accessibility.[162] Empirical studies in other countries also show that more broadly the public is reluctant to engage with policy making initiatives which may be time consuming and perceived as having little impact.[163] The Frimley ICB's Constitution nevertheless explicitly provides for regular participants and observers to attend Board meetings, but leaves leeway to the Board to temporarily remove them from meetings should it choose to "pass a resolution to exclude the public as per the Standing Orders".[164] Regulatory subjects' decision-making abilities can thereby be confined to specific circumstances.

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[158] NHS Frimley, 'NHS Frimley Integrated Care Board Constitution' (2022) < https://www.frimley.icb.nhs.uk/policies-and-documents/how-we-make-decisions/1124-nhs-frimley-icb-constitution/file > 2.1.6 accessed 8 July 2024.
[159] Id., s 3.13.
[160] NHS England, 'Building Strong Integrated Care Systems Everywhere ICS Implementation Guidance on Working With People and Communities' (2021) < www.england.nhs.uk/wp-content/uploads/2021/06/B0661-ics-working-with-people-and-communities.pdf > accessed 8 July 2024.
[161] Id.
[162] Kris Southby and others, 'A Rapid Review of Barriers to Volunteering for Potentially Disadvantaged Groups and Implications for Health Inequalities', (2019) 30 International Society for Third Sector Research 907.
[163] Abelson (n 27).
[164] NHS Frimley, 'NHS Frimley Integrated Care Board Constitution' (2022) < https://www.frimley.icb.nhs.uk/policies-and-documents/how-we-make-decisions/1124-nhs-frimley-icb-constitution/file > 2.1.6 accessed 8 July 2024, s2.3.4.

Accountability and transparency also featured among the Board's 13 core principles. It is suggested that the Board adopts a transparent approach and documents its decisions.[165] Under Title 7, arrangements are set out to ensure that the principles are respected.[166] This Title touches upon scrutiny and decision making, explicitly listing the reasons that would justify a Board's decisions: "a) quality and innovation; b) value integration and collaboration; c) access; d) inequalities and choice; e) service sustainability; f) social value; g) and be subject to appropriate transparency and scrutiny requirements".[167] These are reminiscent of the deliberative approach's deciding criteria, but it is unclear whether they were agreed by members of the Board or imposed as governing principles, which may have stifled an opportunity for bottom-up co-creation.

A commitment to "consult with the local population"[168] is mentioned in the ICB's Constitution, and a set of another 10 principles to govern the relationship of the Board with people and community centres are offered as guidance on how to include people and communities' voices in the decision-making process. The principles suggest that the community should be engaged early in strategic planning to build relations with "excluded groups".[169] Values of empowerment, transparency and accessibility in communication are also presented as essential in order to "tackle system priorities"[170] and to "build on the assets of all partners".[171]

B. Thematic Analysis of Board Meetings' Minutes

[165] Id. s6.2.
[166] Id. s7.3.
[167] Id. s7.4.4.
[168] Id. s9.1.2.
[169] Id. s9.1.3.
[170] Id.
[171] Id.

This section presents the results of our thematic analysis along each of the framework's deliberative dimensions bringing forward the deliberative practices devised by the ICB to implement the duties to reduce health inequalities imposed by the Health and Care Act 2022.

1. Degree and quality of participation

During its initial meeting in July 2022, Frimley's ICB acknowledged that a new decision-making process was needed and that a "new and exciting approach [to] manage shared priorities and challenges together"[172] would be brought in. However, the role of the public, patients, the community and marginalised groups was not mentioned, even though "the agenda was deliberate [sic] framed around population health management, and [the] need to focus to address these strategic goals around health inequalities was paramount".[173] On average, eight members of the public joined Board meetings between July 2022 to January 2024, but the minutes show that their involvement was limited to their attendance. By contrast, "individuals with experience of working in the Local Government, NHS Provider and Primary Care Sector" were specifically called on to take part in the decision-making process because of their "greater expertise".[174] Beyond this example, the minutes do point to substantial mechanisms for reaching out to the community to include stakeholders in the co-creation of policy or in decisions for the allocation of resources that are likely to impact them..

2. Degree of involvement in priority setting

In-depth discussions with the community, service users and marginalised groups are encouraged by NHS England guidance on ICSs.[175] In Frimley, the public is invited to put

[172] NHS Frimley Integrated Care Board, 'Draft Minutes of NHS Frimley Integrated Care Board' (July 2022) < www.frimley.icb.nhs.uk/policies-and-documents/governing-body-meeting-papers/nhs-frimley/july-2022/july-1/972-frimley-icb-papers-19-july-2022-meeting-in-public-final/file> accessed 8 July 2024.
[173] Id.
[174] Id.
[175] Charlotte Augst and others, 'England's health and care bill neglects service users' voice' (2021) 374 BMJ n1979.

forward questions to the Board ahead of meetings, but we note that this opportunity has rarely been taken up.[176] This may be because the associated paperwork lacked accessibility. For instance, literacy skills can present a barrier for marginalised groups particularly in the more deprived areas of the country.[177] It may also be that the public did not have a strong sense of the weight it could carry in the decision-making process, or that it was not aware of the work led by the Board or its existence. Nonetheless, when presented with a question from the public on how to best address lack of access to primary care services, the Board suggested a review of actions and that potential solutions be "comprehensively tested with local people for their views"[178]. This illustrates the consultative and non-strategic role of the public in the review and commissioning of services, which falls short of a deliberative approach. In other parts of the ICS, co-creation of policy is encouraged citing NHS England principles for working with people and communities,[179] but this is not an aspect that is brought forward in the formal meetings of the Board where the public involvement is minimal as illustrated by our analysis.

The minutes highlights the ICSs' strategic focus. The ICB Chief Executive report lists three key areas of for future work: a review of urgent and emergency care; support to children and young people; and planned care access and waiting times.[180] The data collected as part of these areas is presented to the Board,[181] but the extent to which communities were involved in the preparation of reports on these initiatives is not specified.

3. Degree of involvement in the design of accountability mechanisms

[176] NHS Frimley Integrated Care Board (n 172).
[177] Anne Teravainen-Goff and others, 'Selfom-heard voices: Adult literacy in the UK' *National Literacy Trust* (2022) < https://nlt.cdn.ngo/media/documents/Adult_Literacy_2022_report_FINAL.pdf> accessed 8 July 2024.
[178] NHS Frimley Integrated Care Board (n 172).
[179] NHS Frimley, 'NHS Frimley Integrated Care Board Constitution' (2022) < www.frimley.icb.nhs.uk/policies-and-documents/how-we-make-decisions/1124-nhs-frimley-icb-constitution/file > 9.1.3 accessed 8 July 2024.
[180] Id.
[181] Id.; NHS Frimley Integrated Care Board, 'Draft Minutes of NHS Frimley Integrated Care Board' (October 2022) <www.frimley.icb.nhs.uk/policies-and-documents/governing-body-meeting-papers/nhs-frimley/july-2022/december/1289-nhs-frimley-icb-board-papers-meeting-in-public-20-12-22-v2/file > accessed 8 July 2024.

Performance and oversight reports are regularly presented to the Board but with no explicit mention of the involvement of community stakeholders in the preparation of these documents.[182] Nonetheless, the Board puts forward a solution to involve ICS staff (experienced local government staff, NHS and primary care sector providers) more meaningfully in decision making, and to have community members take part in the Board's activities. A "Mirror Board"[183] designed to parallel the composition and structure of the Board is to hold the Board accountable for its decisions. Its non-executive members are to be "recruited from community organisations/wider community".[184] The initiative aims at increasing diversity on the Board and address the "under-representation from people from BME groups, [which has] manifest[ed] itself across the ICS workforce".[185] The Mirror Board is to review and reflect on the papers put forward to the main Board ahead of the meeting and relay any comments or suggestions at the start. Mirror Board members are also encouraged to co-present papers with Board members.

Looking at this initiative, there is potential for members from marginalised groups to be approached and encouraged to put themselves forward for Mirror Board non-executive positions. They may be able to provide crucial "insight, feedback and ideas to senior decision-makers"[186] and benefit from upskilling to eventually join and "support the Board in becoming more representative of the communities it serves".[187] The Mirror Board is also likely to

[182] All NHS Frimley Integrated Care Board meetings during the July 2022 to January 2024 period.
[183] NHS Frimley Integrated Care Board, 'Development of an NHS Frimley Mirror Board' (September 2022) < www.frimley.icb.nhs.uk/policies-and-documents/governing-body-meeting-papers/nhs-frimley/july-2022/september-1/1083-frimley-icb-papers-20-september-2022-meeting-in-public/file > accessed 8 July 2024; NHS Frimley Integrated Care Board, 'Draft Minutes of NHS Frimley Integrated Care Board' (September 2022) < www.frimley.icb.nhs.uk/policies-and-documents/governing-body-meeting-papers/nhs-frimley/july-2022/18-october-2022/1125-nhs-frimley-integrated-care-board-meeting-in-public-18-october-2022/file > accessed 8 July 2024.
[184] NHS Frimley Integrated Care Board, 'Development of an NHS Frimley Mirror Board' (September 2022) < www.frimley.icb.nhs.uk/policies-and-documents/governing-body-meeting-papers/nhs-frimley/july-2022/september-1/1083-frimley-icb-papers-20-september-2022-meeting-in-public/file > accessed 8 July 2024 (a)
[185] Id.
[186] Id.
[187] Id.

improve the overall accountability and transparency of the Board and to focus on targets that may be geared toward service users' experiences rather than system performance.

VII. CONCLUSION

Marginalised groups in England continue to encounter challenges when accessing the NHS, contributing to wider health disparities. The traditional regulatory approaches of *regulation for social purpose* and *regulation for efficiency and patient choice* have brought about and maintained systemic factors contributing to access barriers. System level decision-making for the commissioning and provision of healthcare services need to be regulated with a novel approach to better address these issues.

Deliberative theory provides an alternative to rethink regulation and create greater equity in accessing healthcare services. Discussion and communication are at the heart of this process and constitute an end in itself. Participants' contributions, sharing their lived experiences and perspectives at every stage of decision making also legitimises this form of regulation. The deliberative approach has the potential to help support a deep cultural change by involving more intentionally and meaningfully marginalised groups in setting priorities and making decisions for the commissioning of services that directly impact on their experiences and health outcomes.

To explore the potential of this critical theoretical approach, we focused on the Health and Care Act 2022 as a case study because this reform signals a move towards a more collaborative decision-making model. Guided by the analysis of systemic factors undermining the impact of previous regulatory approaches, we have designed an evaluative framework as a tool to help gauge the extent to which the law and policy propositions in the Act adopt a deliberative approach to decision making. In the event, our critical reading of the governance framework

and operations of the ICB Frimley indeed indicated the beginning of a shift towards a deliberative regulatory approach.

However, more qualitative data around the experiences of non-executive ICB members are needed to assess their ability to move the needle during crucial commissioning meetings. Perhaps the perspectives of Mirror Board members, should this initiative be taken on beyond Frimley, would also give insights on the degree of deliberation and the impact these members can have on their respective boards. A more decisive step would be to reserve at least one position on the Board to a representative of marginalised communities, although how far, in practice, this would then affect the ICBs' decision-making is open to question.

Discussions also need to extend beyond service access problematics. We additionally need to look for creative solutions to foster greater integration in healthcare provision and to build strong partnerships with care services (community and social care) to prevent illness rather than focus on treatment. Here again a deliberative approach based on communication and co-creation is more likely to provide adequate and targeted interventions catering to the unique needs of marginalised groups. This will require bolder solutions in terms of involvement of marginalised communities to give them a direct voice in setting up services that cater to their needs.

1. Evaluative Framework

MODEL FOR LAW AND POLICY ASSESSMENT				
	Deliberative Dimension	*Systemic Factor Addressed*	*Theoretical Principle*	*Evaluative Questions*
(1)	Degree and quality of participation	Inaccurate data and inadequate engagement with local population	During all stages of the deliberative decision-making process (setting decision criteria and argumentative deliberation) participants' preferences are considered on equal footing, including those of marginalised groups	• *What are the mechanisms available to reach out to the regulatory subjects (local or marginalised communities) to include them in the allocative process?* • *Was an inclusive forum established for participants to deliberate? Were the following elements considered: consultation, accountability, openness, trust and transparency*?
(2)	Degree of involvement in priority setting	Disparity in availability & quality of services	Participants are actively engaging in priority setting, allocative decision-making and designing equitable solutions	• *Is the policy a product of discussions and in-depth interactions (deliberations) with communities?* • *To which extent is co-creation encouraged under the policy or was considered during the policy design?*
(3)	Degree of involvement in the design of accountability mechanisms	Excessive Culture of performance	The implementation of the allocative decisions is monitored through horizontal and vertical accountability channels	• *Have accountability mechanisms been designed with the input of communities?* • *Are communities held accountable for their decisions and propositions?*