

## **'If I was Minister of Health': Democratising Healthcare**

*"For 20 years successive governments have pursued a policy that the public hasn't voted for and doesn't want."*

Leys and Player, *The Plot against the NHS* (2011)

### **Introduction**

Sociologist Colin Crouch coined the term 'post-democracy' to describe the changing power relations in 21<sup>st</sup> century capitalist societies such as the United Kingdom, in which corporations and the "politico-economic elite" have taken greater control of the institutions of the state at the expense of popular sovereignty.<sup>1</sup>

Within an increasingly post-democratic society, the NHS is a particularly post-democratic institution. It has been captured by corporate interests, and there is a 'revolving door' between the public and private sectors.<sup>2</sup> It has an unelected leadership in executive bodies with poor accountability,<sup>3</sup> and only rhetorically involves citizens in its running.<sup>4,5</sup>

This essay outlines a proposal for how a new, ideal Minister of Health could democratise healthcare, describing a fundamental restructuring of the institutions and systems that are currently undermining improvements in health outcomes. Part 1 considers representative democracy (that is, government by elected representatives) and proposes a major constitutional change, separating health and welfare from other functions of government. Part 2 considers deliberative democracy – citizen engagement in public decision-making – and proposes how power could be shifted from politicians and corporations into the hands of patients and the public.

### **Part 1: Representative democracy**

#### ***1a – A unified Ministry of Health***

The crises of the First World War and the 1918-19 influenza pandemic galvanised public health activism, which had been gaining pace since the beginning of the 20<sup>th</sup> century (in 1917, campaigners adopted the slogan "It is more dangerous to be a baby in England than a soldier in France"<sup>6</sup>), and in 1919 the first Ministry of Health (MoH) was formed. It was heavily influenced by the socialist reformer Beatrice Webb, who in a 1909 report had

described the causes of poverty as structural, rather than individual, and argued for universal provision of health services by a unified, centralised ministry.<sup>7,8</sup>

The remit of this new ministry was wide, and at different times in the following decades its responsibilities would come to include social housing, welfare, and environmental health (Figure 1). This is not so today, with the Whitehall department responsible for healthcare being entirely separate from the agencies responsible for public health and the ministries responsible for the social determinants of health.

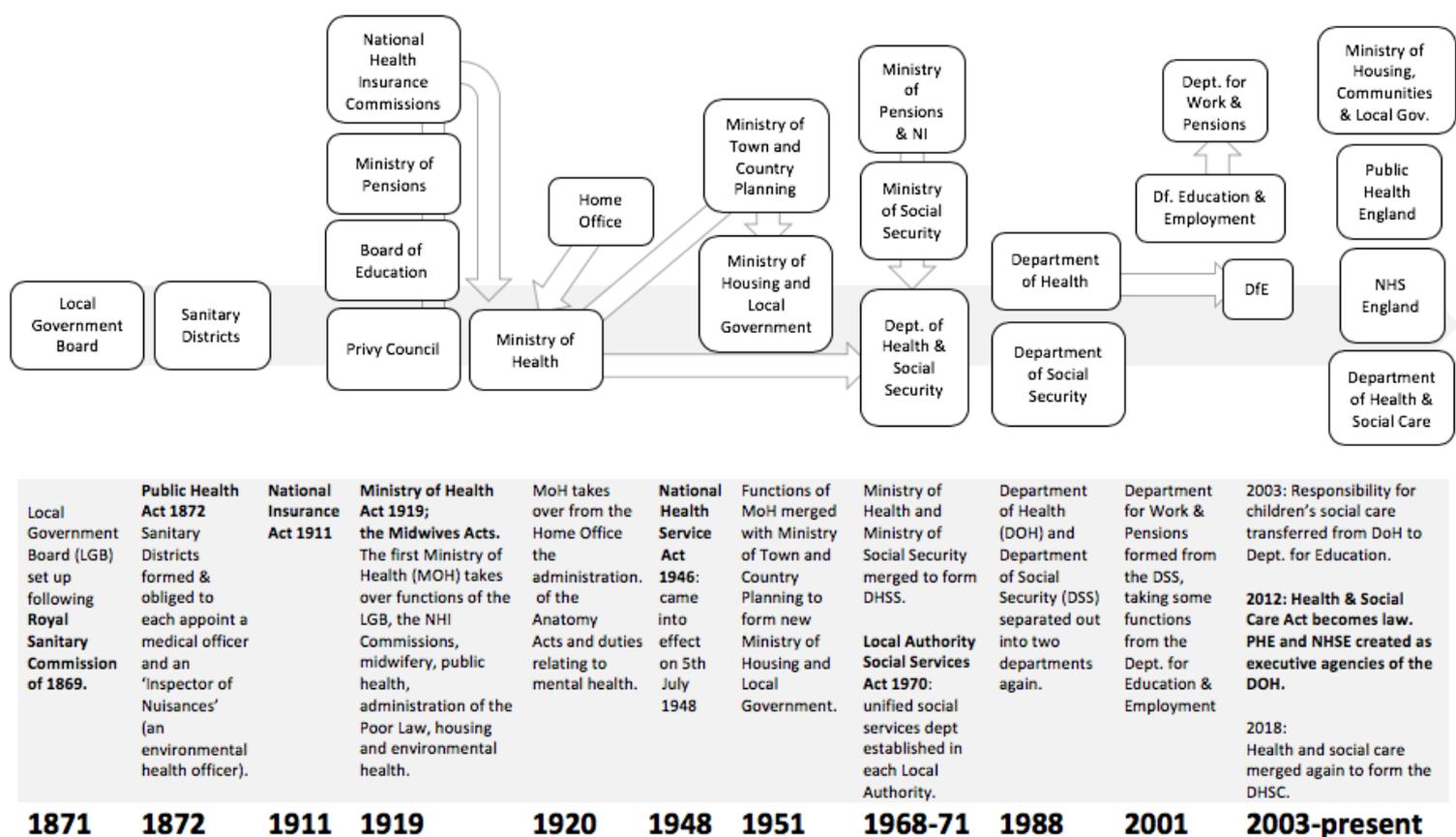


Figure 1. Government-level responsibility and accountability for health and its social determinants, 1872-2020.

Over the last 40 years, those ministries' responsibilities have narrowed as the welfare state has contracted. This, in addition to substantial cuts to local authorities' budgets in the last decade, has been associated with widening inequalities in health and wealth, falling life expectancy in deprived areas<sup>9</sup> and, by one estimate, 150,000 excess deaths since 2010.<sup>10</sup>

To flatten this social gradient in health outcomes, government departments should be realigned to make health ministers accountable for all of health - from its determinants to its outcomes. This framing of problems of social housing, poverty and welfare as problems of health is intended to ensure that public health and the social determinants of health are properly funded, by taking advantage of the willingness of voters to provide healthcare with adequate resources.

### ***1b - The Health Assembly***

A King's Fund survey in 2017 found that 90% of people supported a version of the NHS that is comprehensive, universal and funded by taxation.<sup>11</sup> Further, 67% believed treatments and services should be provided only if they are available to everyone; and 70% believed that the public should be consulted or actively involved in decision-making about the availability of treatments and services.<sup>11</sup>

This is quite different from the NHS as it has been reconfigured in recent years, with increasing out-of-pocket fees,<sup>12</sup> variations in service provision,<sup>13</sup> and higher barriers to access for marginalised groups.<sup>14</sup> In addition, the 2012 Health and Social Care Act (HSCA) has increased fragmentation and privatisation in the NHS and made its decision-making unaccountable.<sup>15</sup> The Act itself was profoundly undemocratic: it was widely reported to have been the co-product of a maverick minister and corporate influence.<sup>16,17,18</sup>

Lord Owen's and Eleanor Smith's recent Bills to reinstate the founding principles of the NHS offer a starting point to inspire the new, ideal, Minister of Health envisaged by this essay.<sup>19</sup> Within an NHS Reinstatement Bill, Clause S3(1) of the 1946 NHS Act should be restored, once again bestowing upon the Minister the "duty to provide" health services. The HSCA removed this duty, thereby opening, according to Tallis and Davis (2013), a "fundamental accountability gap" in health decision-making.<sup>20</sup> The current reorganisation of healthcare in England into Integrated Care Systems (ICSs) clearly demonstrates that unaccountability: ICSs are not statutory bodies, and their development has not been subject to a legislative process.<sup>21</sup>

But a Reinstatement Bill is not sufficient. The short political timescales of a parliamentary democracy combined with its vulnerability to corporate lobbying have subjected the NHS to frequent and disruptive reforms. This is harmful to patients: according to the Organisation for Economic Co-operation and Development, “each reform costs two years of improvements in quality.”<sup>22</sup> Lansley’s removal of Clause S3(1) passed ministerial responsibilities onto NHS England (NHSE), a more politically ‘stable’ institution, and this might conceivably have discouraged such short-termist reorganisation. But this decision also ceded enormous power to unelected officials. For the NHS, accountability and evolutionary change seem to involve a trade-off.

To square this circle our new, ideal Minister of Health should be empowered by a constitutional change: the creation of a Health Assembly and Executive, separate from Parliament and invested with its own tax-raising powers. All current health functions of Government, including those of NHSE and Public Health England, would be transferred to this parallel health legislature and executive (Figure 2). Responsible for devolved local decision-making on health and social care, public health, housing and welfare, Assembly members would be directly accountable to voters in their local health authority area.

Health Assembly elections would be held at the same time as general elections, but candidates would stand on exclusively health-related platforms. Public support for a version of the NHS that is universal, comprehensive and free at the point of use is so consistent that running separate ‘health elections’ should reverse the current pro-market direction of healthcare. Assembly members would be elected proportionally by a Single Transferrable Vote system, resulting in a more pluralistic Assembly. This should limit policy changes to those enjoying broad democratic support and should make frequent large-scale reorganisations less likely.

Since inequalities in those contributing to decision-making results in health policy which excludes the needs of marginalised groups,<sup>23</sup> selection of Assembly members should employ shortlisting quotas<sup>24</sup> of candidates based on age, gender, ethnicity and income/wealth, creating an Assembly that is representative of the population.

To close the ‘revolving door’ between the public and private sectors, commercial conflicts of interest (COI) would be a barrier to Assembly membership. The same COI exclusion would apply to all civil servants, clinicians and advisors with a local or national health policy role.

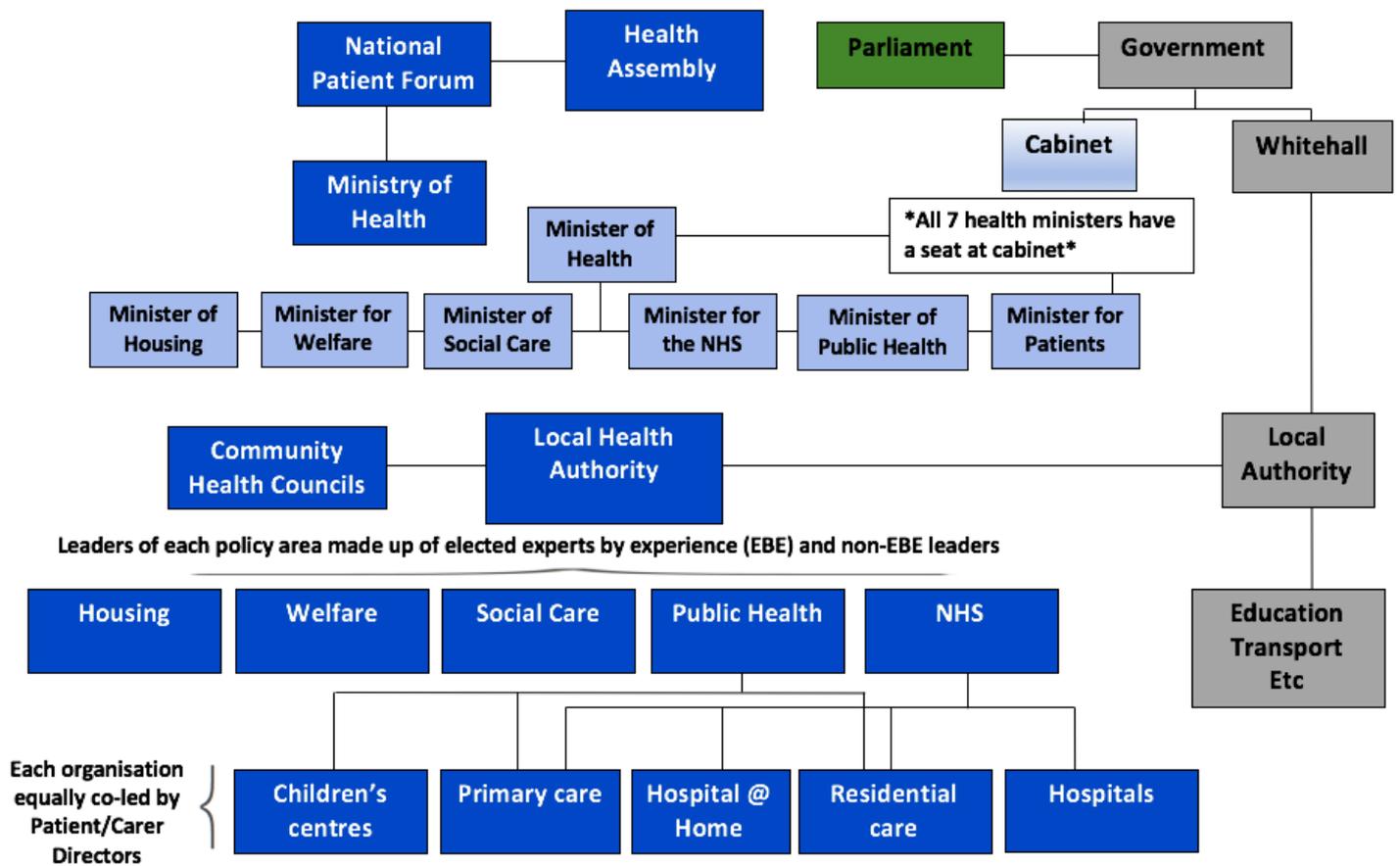


Figure 2. A proposal for enhanced representative democracy in the UK health system.

## Part 2: Deliberative democracy

Many modern political theorists consider a state to be only weakly democratic if it does not allow for continuous, active participation and deliberation by citizens.<sup>25</sup>

Dalton (2017) has shown that countries with higher levels of citizen participation have better performing governments (Figure 3).<sup>26</sup> If the participation involves citizens from a broad range of socioeconomic backgrounds, governance is better still.<sup>26</sup>

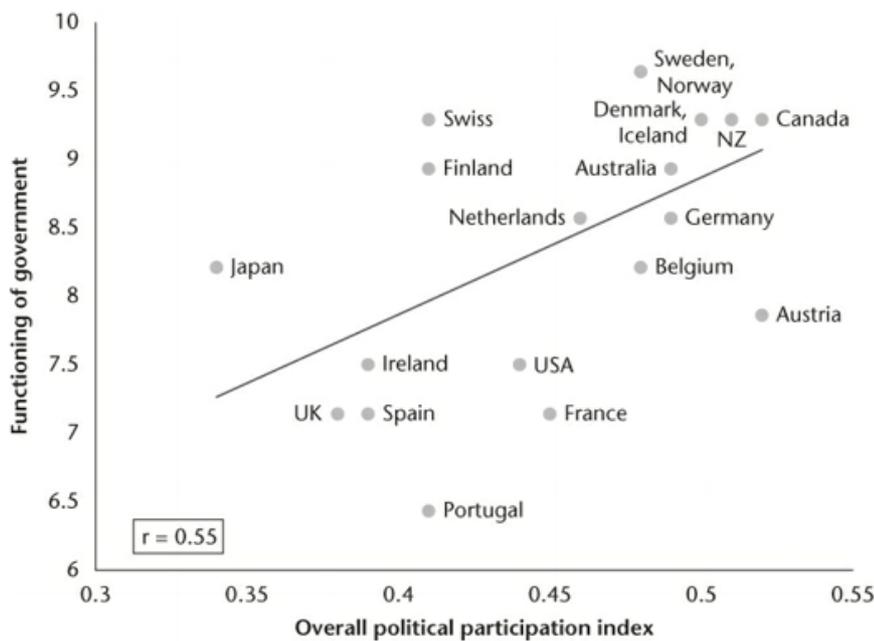


Figure 3. Political participation and quality of governance. (Source: The Participation Gap: Social Status and Political Inequality. Russell J. Dalton, 2017)

In recent years, government reforms to patient and public involvement (PPI) in healthcare have not involved any significant redistribution of power. In an influential 1969 paper, Sherry Arnstein described how “participation without redistribution of power is an empty and frustrating process for the powerless. It allows the powerholders to claim that all sides were considered, but makes it possible for only some of those sides to benefit.”<sup>27</sup> Arnstein described a ‘ladder’ of increasing levels of citizen participation (Figure 4). Current levels of PPI in the NHS are generally described as being on the ‘tokenistic’ rungs.<sup>28,29</sup>

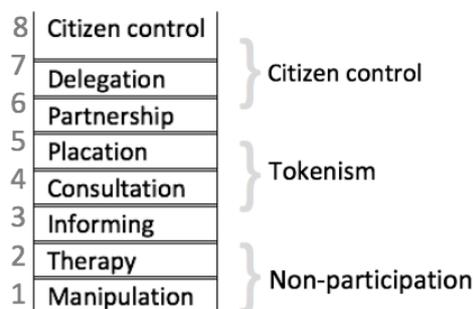


Figure 4. Arnstein’s ‘Ladder of Citizen Participation’ (Adapted from A Ladder of Citizen Participation, Sherry Arnstein, 1969).

Sections 13H and 14U of the 2006 NHS Act and 2012 HSCA stipulate that NHSE and Clinical Commissioning Groups (CCGs) must “promote the involvement of patients”. To enact this duty the government created Healthwatch, linked-up local committees with statutory duties to represent local people’s views on health.

Such ‘health committees’ have a strong international evidence base for improving quality of healthcare,<sup>30</sup> but there is clear evidence that their effectiveness depends on factors such as the inclusion of marginalised groups, careful attention to power asymmetries between the community and other stakeholders, adequate funding, and clearly defined responsibilities.<sup>31,32,33</sup> Healthwatch fails these tests: its national committee is predominantly white,<sup>34</sup> local members’ roles and accountabilities often overlap with the remit of existing organisations,<sup>35</sup> and its budget is modest.<sup>36</sup>

PPI in the NHS has previously been more ambitious and successful. Between 1973 and 2003, Community Health Councils (CHCs) were relatively well funded, independent and autonomous, and had the power to refer disagreements on local health service changes to the Minister of Health. Their abolition in 2003 has been linked to how “they had become very politicised and objected to almost all change”<sup>37</sup> – perhaps unsurprisingly so, given that during the latter part of their existence they witnessed the beginnings of the fragmentation and marketisation of the NHS. It appears that CHCs were seen by government to have too much power, and stood in the way of marketising reforms: subsequent iterations of health committees have had diluted rights and negligible impact.<sup>38,39</sup>

To improve deliberative democracy in the health system, CHCs should be re-established, but radically reformed to operate within devolved local health systems in which they have budgetary and decision-making powers equal to those of the local health authority (Figure 2). At government level, a National Patient Forum would provide expert, deliberative scrutiny of the Health Assembly’s policy-making (Figure 2).

These deliberative structures must be pluralistic. Analyses of the relationship between public preferences and government decision-making have shown that policy outcomes are biased towards the preferences of high-income citizens.<sup>40</sup> Further, if only affluent citizens have access to deliberative democratic processes, support for state welfare provision, on

which poorer citizens depend, is often lower.<sup>41</sup> As such, recent Citizens' Assemblies in Ireland, which are formed so that they are representative in terms of age, gender and ethnicity, and which pay participants for their work, are a model of citizen participation on which CHCs and the National Patient Forum could be based. Van Reybrouck (2016) has praised the Irish deliberative democratic process, arguing that such an approach to democracy "flourishes precisely by allowing a diversity of voices to be heard."<sup>42</sup>

CHCs allow community scrutiny from outside the health system, but their effectiveness would be enhanced if there were also powerful PPI on the inside. To achieve this, there should be an expert-by-experience director of each policy area in every local health authority and a patient/carer director in every health organisation (Figure 2), an innovation that has already been successful in Sussex and Camden.<sup>43</sup>

Finally, effective deliberative democracy requires transparency. Many CCGs have taken advantage of the allowances in the HSCA to meet in private and not publish board papers,<sup>20</sup> corporatisation of Foundation Trusts has allowed previously transparent bodies to claim commercial sensitivity when they have been asked to publish data, and public bodies can be bound by non-disclosure agreements.<sup>44,45</sup> Such barriers are good for businesses but bad for patients: they get in the way of accountability and effective governance, especially deliberative democracy, and are therefore likely to have a negative impact on quality of care. Our new Minister of Health would revoke them.

## **Conclusion**

Current decision-making institutions concentrate power in a politico-economic elite, and the resultant unequal distribution of resources has resulted in wide health inequalities. Recent modes of citizen participation are a simulacrum of democracy, a symptom of a 'post-democracy,' created in a manner that preserves the power of elite institutions rather than redistributing that power.<sup>46</sup>

In the system of governance envisaged in this essay, the interaction of powerful citizen groups with the Assembly, and of the Assembly with the Government, would continue to involve struggles over power. But that is the nature of healthy democracy. By considering the political system in its entirety – from a powerful and engaged citizenry to a pluralistic

and socially representative legislature – this essay has shown how power, wealth and therefore health outcomes could be distributed much more evenly.

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