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ORIGINAL ARTICLE

Territory, values, and health law in a devolved United Kingdom: examining the role of the gift in opt-out organ donation

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Abstract

Devolution since 1998 has seen administrations in England, Northern Ireland, Scotland, and Wales gain distinct powers over a range of policy fields, with health prominent among them. This poses two pressing questions for socio-legal scholarship that we address in this article: to what extent are changing territorial arrangements significant for the substance of United Kingdom (UK) health law and the values by which it is oriented, and what role is played by devolved health law in redefining territories and values within the UK? Informed by perspectives from human geography and policy studies, and drawing on our own qualitative empirical research, we examine recent lawmaking processes in relation to organ donation reform. 'Opt-out' or 'presumed consent' schemes, adopted in sequence in each of the UK countries, appear to challenge the centrality of voluntary altruism, extolled as a fundamentally British value in Richard Titmuss' post-war work on social policy. Our findings confirm that there has been a reterritorialization of values under devolution, with greater emphasis on sub-state identities. However,

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they also indicate the persistence of a common space of policy learning across the UK and an enduring concern with altruism in this area.

1 | INTRODUCTION

Since 1998, devolution has seen governments in Northern Ireland, Scotland, and Wales gain substantial and increasing powers over public health and the delivery of healthcare, with the Westminster Parliament and Whitehall administration now largely responsible for England only. Health has been an area of policy activity in each case. The salience of these developments was highlighted during the COVID-19 pandemic, when lockdown controls of variable duration resulted in the reintroduction of formal borders within the United Kingdom (UK) for the first time in centuries. While there was sustained cooperation at administrative level, political leaders diverged in the relative weight that they gave to the values in play, such as economic liberty and health protection. These differences have also been confirmed by the UK Internal Market Act 2020, passed in the aftermath of the UK's withdrawal from the European Union (EU).[1] This has provoked criticism for cutting across a range of health policies passed by legislatures in the four countries of the UK, again animated by variable value preferences.[2] Two closely related questions can be asked in light of these developments. First, to what extent are changing territorial arrangements significant for health law and values? Second, what role is played by devolved health law in redefining territories and identities and values within the UK? In this article, we present a response to these questions, informed by perspectives from human geography and policy studies, and drawing on the findings of a qualitative empirical study examining policymaking and lawmaking processes across the UK.

We focus specifically on organ donation because this has been an area of recent reform in what is a well-established area of health law, on the part of all three devolved legislatures and Westminster.[3] Over a ten-year period from 2013, measures replaced 'opt-in' with 'opt-out' as the basis for deceased organ donation in each of the UK countries. Put simply, whereas the express consent or, in Scotland, the authorization of deceased adults was previously required for lawful removal of organs, the reforms have created a presumption of consent in all cases where the individual has not registered their unwillingness to donate. A 'soft' opt-out model was adopted, allowing relatives and nominated persons to provide information on any potential refusal previously indicated by the deceased, as distinguished from 'hard' opt-out, which would afford them no role in the process. In formal terms, then, a more or less common human tissue legislative regime that includes the regulation of organ donation[4] has been amended by four distinct acts and sets of regulations.

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[1] M. Dougan et al., 'Sleeping with an Elephant: Devolution and the United Kingdom Internal Market Act' (2022) 138 *Law Q. Rev.* 650.

[2] A note on terminology: in this article, we refer to England, Northern Ireland, Scotland, and Wales as 'countries' of the UK. The alternative term, 'nation', admittedly in wide use, is contentious in the case of Northern Ireland. By the same token, we refer to the UK as the 'state level', as distinguished from the distinct 'sub-state level' established as a result of devolution.

[3] For a comprehensive comparative study of the legislation in each case, see J. A. Parsons, '*Opt-Out' Organ Donation: An Ethico-Legal Policy Analysis* (2025).

[4] For an overview, see A.-M. Farrell and E. Dove, *Mason and McCall Smith's Law and Medical Ethics* (2023, 12th edn) ch. 13.

Moreover, the process of reform was initiated not by Whitehall but in the National Assembly for Wales (now known as Senedd Cymru or the Welsh Parliament), exhibiting the potential for devolved governments and administrations to function as 'policy laboratories'.[5] It then spread to the other countries by way of informal policy transfer, with adoption being favoured by discrete political 'windows of opportunity' in each case.[6] As such, it represents a series of discrete but connected and, therefore, comparable episodes in devolved lawmaking.

Organ donation offers a particularly valuable opportunity to examine the relation between health law, values, and larger-scale developments in the 'territorial constitution'.[7] The shift to opt-out was the subject of public attention in all parts of the UK. Proposals were informed by opinion surveys and formal consultations. High-profile campaigning, within and across the four countries, by patient groups, affected individuals, and sympathetic media was matched by interventions from religious leaders, medical professionals, and ethics experts. While all accepted the need to increase rates of organ donation, there was considerable concern regarding the implications of the reforms for the key value of altruism, according to which donation should take the form of a 'gift' made autonomously (that is, free from coercion and without expectation of financial gain). As anthropologists have shown, ethical and legal regimes that enable the 'gifting' of human tissue are not merely an instrumental matter of linking two individuals, donor and recipient; they are also an important means of sustaining collective identity and defining the limits of belonging, be that universal, or at state and sub-state levels.[8] This is commonly a matter of territory, as much as of relationships – of 'where' we belong, as much as 'who' we are connected to through gifting. Moreover, these scholars have suggested that the link between values, territory, and identity is no finished thing, but rather subject to change and readjustment on an ongoing basis.[9]

The article proceeds as follows. In the next section, we set out the methods used for this study. Section 3 provides a theoretical framework focused on the key concepts of territoriality and territorialization. We argue that the relationship between state space and health law values is reciprocal and dynamic. Health provision and entitlements, including organ donation and supply, are mapped to a specific area, or *territorialized*. Equally, they help to *produce* that territory by integrating its component parts. Section 4 highlights the historic role of altruistic blood and organ donation (gifting), as ordained by legislation, in producing and reinforcing the singular territory of the post-Second World War UK, with reference to the work of Richard Titmuss. Section 5 reflects on the tendency towards *reterritorialization* associated with neoliberal reforms to the welfare state from the 1980s onwards, and with the devolution of powers over health to the countries of the UK. In Section 6, we review and compare recent changes to the law on deceased organ donation in Wales, England, Scotland, and Northern Ireland. In Section 7, based on our

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[5] M. Keating et al., 'Territorial Policy Communities and Devolution in the UK' (2009) 2 *Cambridge J. of Regions, Economy and Society* 51.

[6] See further R. Reed-Berendt et al., 'The Connection–Friction Axis in Devolved Health Policy and Law-Making in the UK: A Case Study of Organ Donation' (2024) 87 *Modern Law Rev.* 1542.

[7] See J. Hunt, 'Subsidiarity, Competence, and the UK Territorial Constitution' in *The Brexit Challenge for Ireland and the United Kingdom: Constitutions under Pressure*, eds O. Doyle et al. (2021) 21.

[8] See C. Waldby and R. Mitchell, *Tissue Economies: Blood, Organs and Cell Lines in Late Capitalism* (2006); A.-M. Farrell, *The Politics of Blood: Ethics Innovation and the Regulation of Risk* (2012); J. Harrington '#weareone: Blood Donation, Terrorism and Dreams of Inclusion in Kenya' (2020) 90 *Africa: J. of the International African Institute* 112.

[9] See for example D. Reubi, 'Blood Donors, Development and Modernisation: Configurations of Biological Sociality and Citizenship in Post-Colonial Singapore' (2010) 14 *Citizenship Studies* 473; D. Seeman, '"One People, One Blood": Public Health, Political Violence, and HIV in an Ethiopian-Israeli Setting' (1999) 23 *Culture, Medicine and Psychiatry* 159; B. Simpson, 'Blood Rhetorics: Donor Campaigns and Their Publics in Contemporary Sri Lanka' (2011) 76 *Ethnos* 254.

empirical research findings, we consider the ways in which the need for organ donation law reform was justified in territorial terms, through variation in the delineation of state, sub-state, and universal values, as well as processes of policy transfer and the explicit consideration of borders across the UK. Section 8 examines the manner in which the gift was both affirmed and reconceived as a cornerstone of the law on deceased organ donation in each UK country, and the factors that were problematized as impediments to its full realization. In Section 9, we return to the two questions set out in this introduction. It will be argued there that our findings show that the move to opt-out organ donation contributes to the reterritorialization of healthcare under devolution. However, at the same time, they also indicate the persistence of a common space of policy learning, oriented to the value of altruism and established through political discourse, legislation, and institutional development in the decades following the Second World War.

2 | METHODOLOGY

Our study seeks to generate novel insights regarding the definition of values and territorial identities within the devolved UK. We do so through focusing on the move to opt-out organ donation in each of England, Northern Ireland, Scotland, and Wales. We draw on both documentary analysis and semi-structured interviews conducted with key individuals involved in the reform process. Approval to conduct this research was granted by Cardiff University School of Law Research Ethics Committee (SREC-211103-02). We began with a review of relevant policy documentation, parliamentary records, and academic commentary on the process of organ donation law reform across the UK. Through this, we identified key actors in each country, who were then invited to participate in an interview. Other potential participants were identified in ‘snowball’ fashion through recommendations from participants. A total of 26 participants were interviewed: four in Scotland, four in Northern Ireland, eight in Wales, nine in England, and one who was active across the whole UK. Participants included ten politicians, six civil servants, six members of activist groups, and three members of National Health Service (NHS) staff.[10] At least one participant from each of these categories was located within each of the four countries of the UK. As a result, we are confident that the study has generated comparable insights in each case, notwithstanding the relatively larger number of participants in England and Wales, which was unplanned. Interviews took place between January and August 2022 and were conducted one to one, with one exception where two participants were interviewed together. Participants were asked questions across several themes, including their involvement in the legislative or policy process, their experiences of it, their understanding of the policy problem, and the key values that they considered were at stake. Interviews were transcribed and then coded manually using qualitative thematic analysis, giving theoretical freedom and generating detailed complex accounts of data. Transcripts were coded independently, with a subsequent comparison of transcripts to ensure consistency and to identify emerging themes. These included the purposes of and motives for the legislation, including the relative importance of distinct and shared values between the countries of the UK. To preserve anonymity, each participant is referred to in this article only by participant number. Our focus on ‘elite’ participants is an admitted limitation of the study, and one that points to the need for a larger project engaging qualitatively with public attitudes. Nonetheless, as will be seen, the move to opt-out was largely initiated within elite circles and transferred between them. We agree with

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[10] We also interviewed a campaigning journalist involved in the reforms.

Mark Simpson, who has argued that elite motivations and aspirations matter for social and health policy under devolution in the UK.[11]

3 | TERRITORY, HEALTH, AND THE STATE

The reciprocal relationship between territory and values has been an important feature of the UK's changing organ donation regime. We can make sense of this evolving relationship with the aid of critical legal geographer David Delaney, who picks out two key terms.[12] *Territoriality* is the generalized expression of a given social order in spatial terms. For example, jurisdiction is the territoriality of the legal system. Territoriality is fundamentally relational. Quarantine, historically the spatial expression of the disease control system, is realized through the delineation of a space, for those are infected, from an adjoining one, for those who are not. As this suggests, territoriality is not simply a neutral background phenomenon. Rather, it is integral to the power and functioning of the social order. *Territorialization* is the dynamic process of sustaining or revising a given territoriality. The disease control system is actively territorialized through representations (such as signage), institutions (such as inspectorates), and values (such as germ theory). It is also subject to *reterritorialization*, as in the shift from physical isolation to the mobile surveillance of suspected disease carriers. Such shifts are often contested and need to be studied qualitatively, attending to changes in representations, institutions, and values.

Territoriality is integral to statehood. States are defined in international law as bounded units of sovereign space, each abutting 'horizontally' on similarly entities.[13] Internally, the state also functions as an ultimate point of reference, assembling component regions into a unified space and aligning the spatial expression of other social orders (such as law, culture, sport, and the economy) with its own. Since the early twentieth century, the reach of the state has been intimately connected with the delivery of healthcare and social welfare. On the one hand, a territorially bounded identity and sense of solidarity is needed to sustain the legitimacy of these redistributive systems;[14] on the other, territorially defined welfare serves a nation-building function, helping to 'define where an individual is a citizen of'.[15] This reciprocal relation is vividly suggested by the names of the most important British schemes (such as *National* Insurance, *National* Assistance, the *National* Health Service).[16] The social order of health and welfare is territorialized through representations (such as nationwide campaigns), institutions (such as integrated workforces), law (such as common entitlement criteria), and values (such as limits to commercialization).[17]

This is an admittedly idealized account of state territoriality. In practice, neither unqualified external sovereignty nor the alignment of social orders with state territory has ever been fully realized, even at the zenith of the 'Westphalian' state-form. Imperial subordination was

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[11] M. Simpson, *Social Citizenship in an Age of Welfare Regionalism: The State of the Social Union* (2022) 9.

[12] D. Delaney, *Territory: A Short Introduction* (2005).

[13] G. Ó Tuathail, '(Dis)Placing Geopolitics: Writing on the Maps of Global Politics' (1994) 12 *Environment and Planning D: Society and Space* 525.

[14] D. Miller, *On Nationality* (1995).

[15] Simpson, op. cit., n. 11, p. 8.

[16] N. McEwen, 'State Welfare Nationalism: The Territorial Impact of Welfare State Development in Scotland' (2002) 12 *Regional and Federal Studies* 66, at 68.

[17] J. Wiggan, 'Contesting the Austerity and "Welfare Reform" Narrative of the UK Government: Forging a Social Democratic Imaginary in Scotland' (2017) 37 *International J. of Sociology and Social Policy* 639.

more common than self-determination. The ambition to establish a uniform system of welfare entitlements was often disappointed. More recently, state territoriality has been subject to 'unsettling' and 'unbundling'.[18] Political, legal, and economic orders are reterritorialized partly to the supranational level through international trade law, and partly to the sub-state level through expanded arrangements for federalism or devolution. These processes have played out in health and welfare, as well as in constitutional law and politics. They are frequently marked by tensions over representations, institutions, and values, as illustrated by the divergent COVID-19 regulations and the UK Internal Market Act (2020) discussed above. 'Unsettling' and 'unbundling' are not the same as 'disappearing', however. The role of states (and sub-states) in guaranteeing citizen entitlements remains anchored in popular expectations. In the next section, we draw on this theoretical frame to explore the role of territory and values in the development of the organ donation system in the UK.

4 | THE NHS AND THE TERRITORY OF THE GIFT

The territoriality of the deceased organ donation regime prior to recent opt-out law reforms needs to be understood within the broader context of British health and social policy in the post-Second World War period. Characterized as a 'social bargain', the welfare state aimed at binding the working class into the political whole.[19] However, as Nicola McEwen points out, its integrative effect was also territorial, drawing in the different countries that make up the UK.[20] This was, of course, achieved through distributing material benefits, but it also had important ideational and normative dimensions. In place of their shared Protestantism and engagement in Empire, both now waning, the welfare state offered Scottish and Welsh citizens a powerful symbol of common Britishness, an official ethos of solidarity, and a set of institutions through which this could be lived in the everyday.[21] Notwithstanding the fundamental constitutional dispute over the status of Northern Ireland, unionists were reassured that there would be no deviation from benefits enjoyed elsewhere in the UK, while nationalists could claim equal social rights, ultimately guaranteed by the Westminster government.[22] Welfare provision, in other words, involved renewing and thickening the territoriality of the UK state.

This territorializing effect was strongest in the case of the NHS. Largely free at the point of use, incorporating the great majority of hospitals and medical staff, and funded from general taxation, the NHS offered people in all parts of the kingdom the sense of belonging to a single, geographically defined community. Admittedly, it was less 'unitary' in practice, with allocation of resources significantly determined by medical professionals and the prior distribution of facilities.[23] Though top-level control was centralized at Westminster, responsibility for implementing policy was conferred on the Scottish Office from the inception of the NHS in 1948 and on the Welsh Office from

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[18] S. Sassen, 'Neither Global nor National: Novel Assemblages of Territory, Authority and Rights' (2008) 1 *Ethics and Global Politics* 61.

[19] Simpson, op. cit., n. 11, p. 59.

[20] McEwen, op. cit., n. 16, p. 66.

[21] See L. Colley, *Britons: Forging the Nation 1707–1837* (1992).

[22] B. O'Leary, *A Treatise on Northern Ireland, Volume II: Control* (2019) 75–88.

[23] D. Wincott, 'Social Policy and Social Citizenship: Britain's Welfare States' (2006) 36 *Publius: The J. of Federalism* 169, at 177; see also J. Stewart, 'The National Health Service in Scotland, 1947–74: Scottish or British?' (2003) 76 *Historical Research* 389.

its creation in 1965. However, even allowing for these features, the NHS remained 'the apotheosis of nationalized social citizenship', especially when considered in terms of representation and values.[24] Historians argue that this pan-British territoriality was sustained by memories of collective effort in wartime, as well as post-war experiences of scarcity and reconstruction. The NHS was thus represented in political speeches, newspaper features, and policy papers as 'a site for patriotic effort', a valuable resource to be managed carefully, and a marker of the nation's progress towards modernity.[25] This was reinforced by the external aspect of the NHS as 'an imperially-resourced service', an enduring focus for 'anti-migrant agitation', and 'an institution heavily reliant on migrant labour'.[26]

The legislative regime governing human tissue, including organ donation, emerged as part of this post-war order. A complex of representations, institutions, and values, it was also congruent with, and contributed to, the territoriality of the post-war state. Most influential in this regard was Richard Titmuss' 1970 text *The Gift Relationship*.[27] He put forward three related claims in defence of the UK's voluntary, non-coercive, and unremunerated blood donation system – claims that have shaped law and policy on organ donation too.[28] First, non-market mechanisms were likely to be safer than those that depended on paid donors, as in the United States (US). Second, commercial markets in blood were inefficient and wasteful, creating both surpluses and shortages. Third, he argued that gifting created and reinforced social bonds, not only in face-to-face relations, but also between strangers.[29] For Titmuss, social policy performed an indispensable, integrative role in industrial societies, overcoming divisiveness. As he put it, 'the grant of the gift or unilateral transfer – whether it takes the form of cash, time, energy, satisfaction, blood, or even life itself – is the distinguishing mark of the social'.[30]

Titmuss' reference to the gift of 'life itself' was likely to have evoked the deaths of servicemen and women during the Second World War among his audience in 1967. As we suggested above, in relation to the NHS, the rhetorical topos of sacrifice during war is commonly associated with the topos of the nation, and the two have historically been linked in campaigns to promote blood donation. The social order thus described by Titmuss was expressed spatially in national rather than universal terms. For him, the cultivation of altruism depended on concrete programmes of political change implemented within the territory of a given state.[31] In particular, the socially integrative effect of the blood system in the UK could only be understood by attending to the 'origin, development, and values of the NHS'.[32] Marked by a sense of 'solidarity and social duty',

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[24] Wincott, id., p. 176.

[25] R. Bivins, 'Commentary: Serving the Nation, Serving the People: Echoes of War in the Early NHS' (2020) 46 *Medical Humanities* 154.

[26] D. Fitzgerald et al., 'Brexit as Heredity Redux: Imperialism, Biomedicine and the NHS in Britain' (2020) 68 *Sociological Rev.* 1161, at 1163.

[27] R. M. Titmuss, *The Gift Relationship: From Human Blood to Social Policy* (1970/1997).

[28] See further A.-M. Farrell, 'Altruism, Markets, and the Importance of the Social Contract in Healthcare: Richard Titmuss's *The Gift Relationship*' in *Leading Works in Health Law and Ethics*, eds S. Fovargue and C. Purshouse (2023) 9.

[29] K. Zeiler, 'Neither Property Right nor Heroic Gift, neither Sacrifice nor Aporia: The Benefit of the Theoretical Lens of Sharing in Donation Ethics' (2014) 17 *Medicine, Health Care and Philosophy* 171, at 174.

[30] R. M. Titmuss, speech to Social Administration Association, 17 July 1967, quoted in P. Fontaine, 'Blood, Politics, and Social Science: Richard Titmuss and the Institute of Economic Affairs, 1957–1973' (2002) 93 *Isis* 401, at 412.

[31] Titmuss, op. cit., n. 27, p. 203.

[32] Id., p. 60.

the NHS was, he claimed, ‘the perfect example of British society’s grandeur’.[33] Titmuss’ writing is animated by a sense of exemplarity vis-à-vis the US and other countries. The UK was pioneering new institutions and the use of modern technologies for health, inspired by values of altruism, voluntariness, and efficiency, from which others could learn. In the period described by Titmuss, deceased organ donation was (lightly) regulated by the Human Tissue Act 1961, which permitted removal where the deceased had given permission or there was a reasonable belief that they had expressed no objection, or where their spouse or close relatives did not object.[34] In practice, organs were not removed without the agreement of families. Donor cards, first introduced to the UK in 1971, were intended to evidence individual consent and commitment to donation within this context.[35]

5 | RETERRITORIALIZING: NEOLIBERALISM AND DEVOLUTION

The post-war territoriality of healthcare and social welfare was ‘unsettled’ and ‘unbundled’ in the two decades from 1979. Its congruence with that of the UK state, particularly regarding policies and values, was challenged by neoliberal reformers, on the one hand, and by campaigners for devolution to Scotland and Wales, on the other. In reforming welfare, Conservative governments under Margaret Thatcher and John Major retained a spatial focus on the UK, as a whole, but challenged its positive association with organized altruism and non-market values. They claimed, instead, that generous entitlements and professional discretion were functioning as impediments to choice and efficiency and, thus, as barriers to native British entrepreneurialism.[36] Critics argued, against Titmuss, that introducing competition into the provision of healthcare and social services was morally defensible and would contribute to reversing the UK’s economic decline.[37] This rearticulation of values informed a suite of NHS reforms, including the formal pricing of inputs and outputs, external management to limit professional discretion, the creation of ‘internal markets’ for care, and the representation of patients as consumers rather than public-spirited citizens.[38] Neoliberal changes were only partial, however. Access to NHS care remained generally free at the point of use. Blood collection continued to be based on voluntary, altruistic donation within the UK, albeit that shortfalls of blood products were made up by purchases from other countries, most notably the US.[39] In addition, the Human Organ Transplantation Act 1989 criminalized the purchase of organs from living donors, putting the gift on a statutory footing.

Opponents of this shift focused on the symbolic ambitions of Conservative governments as much as their practical effects. Many in Scotland and Wales, where the negative social impact of reforms were particularly felt, understood the turn to be a form of ‘contract breaking’ – a

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[33] Fontaine, op. cit., n. 30, p. 434.

[34] Human Tissue Act 1961, s. 1(1).

[35] D. Price, ‘The Human Tissue Act 2004’ (2005) 68 *Modern Law Rev*. 798, at 799.

[36] McEwen, op. cit., n. 16, p. 75.

[37] Fontaine, op. cit., n. 30, p. 434.

[38] See N. Timmins, *The Five Giants: A Biography of the Welfare State* (2001, 2nd edn). Conservative reforms were significantly influenced by the Institute of Economic Affairs, whose director Arthur Seldon had been Titmuss’ chief antagonist in the debate over paid blood donation: Fontaine, op. cit., n. 30, p. 408.

[39] This practice, more prevalent in England and Wales than elsewhere, had deadly consequences with the advent of the HIV/AIDS pandemic: see V. Berridge, *AIDS in the UK: The Making of Policy, 1981–1994* (1996).

repudiation of the bargain between classes and countries of the UK.[40] This critique was adopted by campaigners for devolution in the 1980s and 1990s. Inverting the Conservative position, they retained the post-war focus on organized altruism and non-market values, yet challenged its automatic association with the state territory of the whole UK. Neal Ascherson clarified what was at stake here, in comments concerning Scotland, but equally applicable to Wales, and to a certain extent Northern Ireland:

> [T]he mania for privatising never made sense here, in a country whose tradition is communitarian rather than individualist, deeply suspicious of its own and everyone else's elites, obsessive about equality … It upholds beliefs which were once shared all over the UK: that health and prescriptions, school meals and university education, care and public transport for the old, should all be free, the state's honouring of the contract between citizen and ruler.[41]

Legislative devolution to Northern Ireland, Scotland, and Wales in 1998 allowed a partial reinstatement of post-war welfarism, threatened by Conservative reforms, and the reassertion of sub-state traditions previously absorbed into a pan-British identity.[42] The Labour government in Westminster, now by and large responsible for many areas of social policy in England only, retained neoliberal reforms initiated by its Conservative predecessors.[43] This contrasted with the approach taken in Edinburgh, which undid them, returning to cooperation and a restored role for the medical professions within the Scottish NHS, while Cardiff adopted a still more radical strategy, de-emphasizing acute clinical care within a more holistic, public health-centred approach, including a stronger role for local authorities.[44] Belfast retained the unique merger of health and social care that had been in place since the 1970s, though admittedly in substance policy tended to track that adopted for England.

While opinion polling consistently confirms support for devolution, it has also indicated a desire for similar levels of welfare across all four countries.[45] The reterritorialization of healthcare provision has thus been characterized as a process driven by political elites, particularly in Scotland and Wales.[46] This motivation was most clearly expressed by former Welsh First Minister Rhodri Morgan in a widely reported speech of 2002 concerning the future of the NHS. His aim, he said, was to put 'clear red water' between Cardiff and Westminster – territorial separation marking a difference in institutions and values.[47] Wales was the birthplace of the NHS, via its founder

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[40] McEwen, op. cit., n. 16, p. 66; see also N. Davies, 'The Language of Priorities: Aneurin Bevan, Welsh Labour and the Politics of the Past' (2024) 26 *Brit. J. of Politics and International Relations* 62.

[41] N. Ascherson, 'Return to Babylon' *Sunday Herald*, 31 October 2010, quoted in A. Law and G. Mooney, 'Devolution in a "Stateless Nation": Nation-Building and Social Policy in Scotland' (2012) 46 *Social Policy and Administration* 161, at 169.

[42] D. Béland and A. Lecours, *Nationalism and Social Policy: The Politics of Territorial Solidarity* (2008) 103.

[43] S. L. Greer, 'Devolution and Health in the UK: Policy and Its Lessons since 1998' (2016) 118 *Brit. Medical Bull.* 17.

[44] J. Harrington et al., 'Towards a Welsh Health Law: Devolution, Divergence and Values' (2022) 72 *Northern Ireland Legal Q.* 1.

[45] See further A. Henderson et al., 'Reflections on the "Devolution Paradox": A Comparative Examination of Multilevel Citizenship' (2013) 47 *Regional Studies* 303. Recent data suggests a moderately greater concern with social equality in Scotland than in England: see C. Deeming, 'Social Inequality: Is Scotland More Nordic than Liberal?' in *British Social Attitudes: The 38th Report*, eds E Clery et al. (2021), at <https://natcen.ac.uk/sites/default/files/2023-08/bsa38_social-inequality.pdf>.

[46] Id.

[47] See D. S. Moon, 'Rhetoric and Policy Learning: On Rhodri Morgan's "Clear Red Water" and "Made in Wales" Health Policies' (2012) 28 *Public Policy and Administration* 306, at 308.

Aneurin Bevan – a small country, a community of communities, inevitably privileging solidarity over individualism and collective provision over markets. While Titmuss had emphasized the UK's exemplarity in opposition to the US, Scottish and Welsh distinctiveness was asserted vis-à-vis Anglo-British neoliberalism. While Titmuss had problematized markets in human tissue and healthcare, Scottish nationalists and Welsh Labour saw constitutional arrangements that concentrated power at Westminster as the key threat to welfare. This congruence of territory with values and representations in health and social policy has been much less pronounced in Northern Ireland due to fundamental disagreement over its constitutional status, along with the repeated collapse of arrangements for devolved government.[48] The response of institutional leaders and civil servants, seeking to ensure continuity in administration, has been to take a low-key and pragmatic approach to policy, maintaining 'parity' with developments at Westminster.[49]

In this section, we have considered the reterritorialization of health and welfare in the period since the turn to neoliberalism in 1979 and devolution in 1998 – both key political contexts for the recent introduction of opt-out regimes in the countries of the UK. In the next, we focus more closely on the legal content of those regimes and on their relation to legislative and institutional reforms regarding healthcare generally and organ donation in particular.

6 | LEGISLATING FOR ORGAN DONATION: OPT-IN TO OPT-OUT

The legislative background to the opt-out organ donation law reforms in England, Wales, and Northern Ireland is provided by the Human Tissue Act 2004 (HTA 2004), passed in the aftermath of revelations that tissue from deceased child patients had been taken for scientific purposes at Alder Hey and other hospitals without the consent or knowledge of their families over more than a decade.[50] The HTA 2004 established an opt-in system for organ donation, based on informed consent, rather than simply an absence of objection.[51] It also set out criteria of lawfulness for deceased and living organ donation in a much more detailed way than those of the 1961 and 1989 acts, of which previous mention has been made. The Human Tissue Authority was established to oversee detailed implementation of the act, working to a varying extent with existing institutions to regulate the organ donation and transplantation services in the UK. The Human Tissue (Scotland) Act 2006 (HTA 2006) was framed in broadly similar terms, except for the preferred use of the term 'authorisation' for organ donation. This act is implemented by ministers in the Scottish government, who collaborate with the Human Tissue Authority in some (but not all) respects.[52] Both acts include a ban on the commercialization of tissue transfer, whether from deceased or living donors. Both put opt-in systems of donation at the heart of the respective legislative regimes.

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[48] Keating et al., op. cit., n. 5, p. 61.

[49] Simpson, op. cit., n. 11, p. 118. Abortion law had been a conspicuous exception to this convention, with a more or less complete ban in force in Northern Ireland, but that was reversed in 2019: see S. Sheldon et al., *The Abortion Act 1967: A Biography of a UK Law* (2022) 118–119.

[50] See House of Commons, *The Royal Liverpool Children's Inquiry Report* (2001), at <https://assets.publishing.service.gov.uk/media/5a74a0b5e5274a410efd121e/0012_ii.pdf>.

[51] Price, op. cit., n. 35.

[52] See Farrell and Dove, op. cit., n. 4, pp. 422–426, pp. 433–442.

A move from opt-in to opt-out was proposed by a series of private members' bills at Westminster before and during passage of the HTA 2004, all of which were unsuccessful.[53] The status quo was endorsed by the Organ Donation Taskforce in its 2008 report to the UK government. Echoing the evidence of religious groups and some ethicists, it feared that opt-out could 'undermine the concept of donation as a gift, erode trust in NHS professionals and the Government, and [thus] negatively impact on organ donation numbers'.[54] It argued that improved infrastructure for the retrieval and transfer of organs would prove a more effective and less controversial means of improving donation rates. NHS Blood and Transplant (NHSBT), established subsequent to the Taskforce report, was charged with implementing these systemic goals. Responsible for blood donation services in England and organ transplantation across the UK, NHSBT places its specialist coordinating staff in trusts and on health boards to engage with families and clinicians. It also manages the allocation process on a UK-wide basis, offering matched organs to individuals on the waiting list, as well as promoting donation among the general public.[55]

Failure to make progress on opt-out in the UK parliament saw attention shift to the devolved legislatures, first in Wales.[56] The law reform process there was initiated by the main opposition party, Plaid Cymru, and then adopted and led by successive Labour administrations, culminating in passage of the Human Transplantation (Wales) Act 2013. Our empirical research findings reveal that the British Medical Association (BMA) played a discreet but influential advocacy role from the outset, which was repeated elsewhere in the UK.[57] NHSBT was also widely consulted as a source of neutral scientific advice on the systemic implications of the change. In Scotland, opt-out had been considered in a review that took place in 2013, but the Scottish government preferred at the time to wait for evidence on the success or otherwise of the Welsh reform. A subsequent private member's bill from the opposition Labour Party was lost in Scotland, due in significant part to the reservations of specialist medical professionals. However, it provided the occasion for renewed action by the Scottish government, including a public consultation, and eventually led to the adoption of the Human Tissue (Authorisation) (Scotland) Act 2019.

At Westminster too, opt-out reform for England was initiated by a private member's bill that gained cross-party backing, including that of Prime Minister Theresa May. This was particularly notable, given that it occurred at a time of profound division in Parliament over the UK's withdrawal from the EU. Strongly supported by the tabloid newspaper, the *Daily Mirror*, the Organ Donation (Deemed Consent) Act 2019 is known colloquially as 'Max and Keira's Law', in reference to the case of Keira Ball, whose parents had agreed to her heart being offered for transplant to nine-year-old Max Johnson in 2017. In Northern Ireland, the concerns of medical professionals, along with the collapse of the devolved institutions, also impeded efforts to change the law. The consociational form prescribed for the Executive in Belfast, as a means of manag-

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[53] See for example 'Transplantation of Human Organs Bill', Hansard, 364 *HC Debs* (16 March 2001) cc 1335; 'Organ Donation (Presumed Consent and Safeguards)' Hansard, 282 *HC Debs* (20 March 2002) cc 325.

[54] Department of Health, *The Potential Impact of an Opt-Out System for Organ Donation in the UK: An Independent Report from the Organ Donation Taskforce* (2008) para 1.12, at <https://webarchive.nationalarchives.gov.uk/ukgwa/20210504111523/https:/nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/4245/organsfortransplantstheorgandonortaskforce1streport.pdf>.

[55] See further NHS Blood and Transplant, 'What We Do' *NHS Blood and Transplant*, at <https://www.nhsbt.nhs.uk/what-we-do/>.

[56] The individual and institutional drivers of change in each of the four countries, the opportunities and obstacles to this, and the interrelation between them are discussed in Reed-Berendt et al., op. cit., n. 6.

[57] Participant 21.

ing inter-communal disagreement, has tended to slow social reform or to reduce its scope to the 'lowest common denominator'.[58] However, fresh impetus was provided in this case by a campaign launched in 2018 by the parents of Dáithí Mac Gabhann, a two-year-old boy who was then on the waiting list for a heart transplant, with support from the British Heart Foundation and Kidney Care UK. Eventually, commitments from the leaders of all main parties and the restoration of power-sharing institutions in Belfast in 2020 facilitated the passage of the Organ and Tissue Donation (Deemed Consent) Act (Northern Ireland) 2022, popularly known as 'Dáithí's Law'.

The Welsh, English, and Northern Irish acts each introduce opt-out by way of amendment to the HTA 2004. The Human Transplantation (Wales) Act 2013 is the most broadly formulated, providing that if an adult dies in circumstances where their organs may be donated, they will be deemed to have consented to donation unless they have an express decision to opt out in force, or if a close friend or relative objects on the basis that the person would not have wanted to donate.[59] The latter provision ensures that a 'soft' opt-out legislative regime is in place, rather than 'hard' opt-out, which would have permitted medical professionals to disregard the views of relatives and others. The degree of cogency required for the evidence to be accepted is not specified. These requirements are more tightly drawn in England and Northern Ireland, where an adult is deemed to have consented to donation unless someone in a 'qualifying relationship' with the deceased immediately before their death provides information that 'would lead a reasonable person to conclude' that they would not have consented.[60]

Consistent with the distinct terminology and scheme of the HTA 2006, which it amends, the Human Tissue (Authorisation) (Scotland) Act 2019 provides that 'deemed authorisation' will apply to deceased organ donations where an adult has made no express 'authorisation' and has not opted out.[61] Evidence concerning the latter can be provided by 'persons' unspecified, a category that is wider than that adopted elsewhere in the UK.[62] The scope of exemption from opt-out is similar in all four countries, and includes under-18s (under-16s in Scotland) and adults who lacked mental capacity for a significant period prior to their death. Persons not resident within England, Northern Ireland, Scotland, or Wales for a period of 12 months before their death are also excluded; express consent to donation is required in such cases.[63] Health authorities in all countries except England are placed under a duty to raise awareness of the change in the donation system.[64]

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[58] D. Birrell and A. M. Gray, 'Coalition Government in Northern Ireland: Social Policy and the Lowest Common Denominator Thesis' (2011) 11 *Social Policy and Society* 15.

[59] Human Transplantation (Wales) Act 2013, s. 4(4).

[60] Organ Donation (Deemed Consent) Act 2019, s. 1(4); Organ and Tissue Donation (Deemed Consent) Act (Northern Ireland) 2022, s. 1(4). Each adopts the hierarchy of qualifying relationships set out in Human Tissue Act 2004, s. 27(4).

[61] Human Tissue (Authorisation) (Scotland) Act 2019, s. 7(2).

[62] Id.

[63] Human Transplantation (Wales) Act 2013, s. 5(3); Human Tissue (Authorisation) (Scotland) Act 2019, s. 7(2); Organ Donation (Deemed Consent) Act 2019, s. 1(5); Organ and Tissue Donation (Deemed Consent) Act (Northern Ireland) 2022, s. 1(4).

[64] Human Transplantation (Wales) Act 2013, s. 2(1); Human Tissue (Authorisation) (Scotland) Act 2019, s. 2(1); Organ and Tissue Donation (Deemed Consent) Act (Northern Ireland) 2022, s. 1(7).

7 | OPT-OUT AND THE IMPORTANCE OF TERRITORY

The institutional and legal reforms considered above effected a complex reorientation of the legislative regimes governing deceased organ donation in the UK. On the one hand, in the aftermath of Alder Hey, geographic unevenness in professional practice was to be reduced through more detailed regulation and greater central control via the Human Tissue Authority and Scottish ministers respectively, as well as NHSBT. On the other hand, the reach of these bodies varied, being focused sometimes on a single country, sometimes two or more in combination, and sometimes on the whole UK. More recently, opt-out statutes have been superimposed on this set of arrangements, each limited to England, Northern Ireland, Scotland, and Wales respectively. However, the territoriality of social orders, governing organ donation or healthcare more generally, is not simply a function of institutional arrangements. Rather, as our theoretical framework has suggested, it is also shaped by ideas and values. This section examines whether, and how, opt-out reform in the four countries was conceived of in explicitly territorial terms by its elite proponents. As we will see, this has three dimensions: policy learning and emulation between Cardiff, Edinburgh, Belfast, and Westminster; boundary work at the UK's internal and external borders; and perceptions of opt-out reforms as expressing distinctly Welsh, Scottish, Northern Irish, or English values.

7.1 | 'Watching Wales': legislative innovation and policy learning

Policymakers in Wales were aware of the wider significance of the reforms there in responding to calls to take the lead in addressing the organ shortage. It was observed that the Welsh government 'had the world's media … camped out on their doorstep … UK national, but also some global media … so it really did have a light shine on Wales that perhaps we'd never had before on an issue of global interest'.[65] Indeed, opt-out reform also revealed the potential for devolved self-government to facilitate policy change in line with popular wishes, with one participant noting in the Welsh context that 'there are things that we've shown are possible that can be done in Wales that could be applied across the UK'.[66] However, this demonstration effect was understood in different ways in each of the other three countries. For campaigners in Northern Ireland, one participant viewed it as providing 'a level of reassurance to clinicians here who maybe still harboured some concerns about it, that "Look, Wales, just across the water – they've made it work and it hasn't had any negative effects".'[67] In Scotland too, an initial focus on countries such as Spain, Belgium, and Israel shifted to its UK neighbour:

> When we were going through the government process … there was more and more evidence coming out from Wales, which was really, really helpful [in countering] that challenge, that argument of 'Oh they've got a different healthcare system to us', because actually it's a very similar system in Wales.[68]

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[65] Participant 4.

[66] Participant 13.

[67] Participant 9.

[68] Participant 7.

The Welsh opt-out reform had not provoked a popular backlash. Indeed, NHSBT data showed that consent rates, if not (yet) actual donations, had increased following its adoption and implementation.[69] As one advocate working on a UK-wide basis observed, it was 'almost like a controlled trial … a perfect opportunity to find out what would happen, because everything else was the same. [Only the law] changed.'[70]

Proponents of opt-out for England were considerably more reticent regarding Cardiff's initiative, accepting that it was rare for them to admit to learning in this way. Their scepticism regarding the motives of the devolved governments had been confirmed during the subsequent COVID-19 pandemic when, 'looking at it from an English point of view, it's quite clear that both Wales and Scotland deliberately made slight changes to their policies to show difference'.[71] This general wariness was reinforced at the time by the parliamentary politics of devolved health. Among members of parliament (MPs), the following was noted:

> [There were] sensitivities around citing the example of Wales because … the issue of the NHS in Wales has been used as a bit of a political football … Labour MPs would get up at Prime Minister's Questions on occasions to express concern about the Conservative government's handling of the NHS in England. It was often the kind of counter-response from a Conservative minister to essentially make criticism of the Labour Welsh Assembly's handling of the NHS in Wales.[72]

By contrast, and away from the parliamentary context, developments in Wales were quietly but closely observed, leading to informal consultation between policymakers, facilitated on occasion by professional and charitable organizations in and across the four countries.[73] In Northern Ireland, for example, there was an open engagement with developments taking place elsewhere in the UK. This was born not only of a wish to learn and emulate, but also of concerns on the part of policymakers that a scenario might arise 'where changes are brought in in the rest of the UK and Northern Ireland's the only one left standing'.[74] Indeed, such concerns allowed 'mounting pressure' to be applied to reluctant legislators by campaigners based not only in Belfast but also in London.[75] As one campaigner observed, 'we kept on saying … England has done it, you know, and [Northern Ireland is] the only nation in the Union that [doesn't] have it'.[76] As well being an aid to political persuasion, the desire for 'parity' also shaped the development of the legislation itself.[77] Officials recognized that 'we could write it completely fresh, but if it works in England, it will work here, so it was a case of us tweaking it'.[78] Unsurprisingly, perhaps, the provisions of the

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[69] See J. Douglas and A. J. Cronin, 'The Human Transplantation (Wales) Act 2013: An Act of Encouragement, Not Enforcement' (2015) 78 *Modern Law Rev*. 324.

[70] Participant 21.

[71] Participant 2.

[72] Participant 25.

[73] Participants 4 and 25.

[74] Participant 9.

[75] Id.

[76] Participant 17.

[77] This has been seen more generally as a 'prevailing ethos of administrative conservatism': A. M. Gray and D. Birrell, 'The Structures of the NHS in Northern Ireland: Divergence, Policy Copying and Policy Deficiency' (2012) 38 *Public Policy and Administration* 274.

[78] Participant 11.

Northern Irish opt-out legislation largely replicate those contained in the Westminster legislation, as noted above.

7.2 | 'Borders and boundaries': limits of the gift

An awareness of territorial limits both encouraged the sequence of moves to opt-out and shaped the detail of ensuing law reform. The need for coordination and consistency in organ donation rules was reinforced by wider controversies regarding mobility for healthcare across the internal border between England and Wales, as regards both funding and waiting times.[79] As one Westminster-based respondent put it, 'when you get into conversations about Wales, inevitably you get into conversations about borders and boundaries. And if you live in Shrewsbury, you're not that far from Wales, but you're in England … so … it was happening in a part of the United Kingdom'.[80] The external border between the UK and the Republic of Ireland was a matter of concern in Northern Ireland. Some denied that that frontier should have any moral significance, with one participant noting that

> Ireland is a small enough island – we're one hour and 50 minutes from Dublin, you know? There are children, waiting on the gift of a heart transplant as well and they have to fly to the UK, so they're the same people as us, you know?[81]

Others were more cautious, recognizing that differential conditions for access to healthcare produced patterns of mobility, which had to be addressed by policymakers. As one participant noted, while what was happening in the rest of the UK

> doesn't really cause any issues [for us], there's a lot of people in the Republic of Ireland who work in Northern Ireland, but also try and have their health service in Northern Ireland because it's free at the point of service, as opposed to having to pay for it.[82]

Of similar import was the case of military servicepersons 'flying in and out, and doing tours of duty' in Northern Ireland.[83]

In each case, the opt-out legislation passed sought to address these territorially defined concerns through the inclusion of residence requirements of up to two years prior to the application of opt-out, as noted above. The effect of this requirement is that, if an individual dies in a country of the UK where they have not been residing, removal of their organs will continue to be subject

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[79] For a more extended discussion, see J. Harrington and A.-R. Hampton, '"Border Country": Health Law in a Devolved UK' (2024) 31 *Medical Law Rev*. 229.

[80] Participant 25.

[81] Participant 10. Informal cross-border cooperation on organ transplantation is long established: see for example Department of Health, *Report of the Buggins Commission on the Allocation of Organs to Non-EU Residents* (2009) para 2.6, at <https://bts.org.uk/wp-content/uploads/2016/09/Buggins-Report-ALLOCATION-OF-ORGANS-TO-NON-UK-EU-RESIDENTS.pdf>. Further impetus is likely to be added by the recent adoption of a 'soft' opt-out donation regime in the Republic of Ireland under the Human Tissue (Transplantation, Port-Mortem, Anatomical Examination and Public Display) Act 2024.

[82] Participant 11.

[83] Id.

to opt-in rules.[84] However, the residence requirement only applies to organ donation, not allocation. Accordingly, organs obtained under the opt-out system in one country can be distributed by NHSBT to anyone in the UK in accordance with agreed allocation criteria. This asymmetry allowed Edwina Hart, the Welsh Health Minister who had initiated the reform process, to argue that 'Wales as a nation is being altruistic in terms of what it wants to undertake because these organs cannot be guaranteed to the people in Wales'.[85] This perception of collective altruism was reinforced, in the view of Wales-based participants, by the early commitment of Cardiff to fund 50 per cent of the cost of adapting NHSBT's UK-wide register to facilitate the recording of preferences under opt-out, beyond Wales' normal proportion of 18 per cent.[86]

7.3 | 'A very altruistic society': different values

Opt-out was most openly associated with sub-state identity in Wales, with the reforms seen to be consistent with other initiatives pioneered under devolution, including the domestication of the UN's Sustainable Development Goals in law and public administration.[87] As noted by one participant, 'I think on social stuff, Wales often leads the way, actually. You know we have the Well-Being of Future Generations Bill. I think we have a very socially conscious government, trying to do the best for all its citizens'.[88] This capacity to innovate was possible due to characteristics seen as typically Welsh. First, 'we are a small nation, where people do know each other … [T]here is a high level of trust among those professionals who work together, which made it easier to have very open discussions.'[89] Second, Wales is 'a very altruistic society … I've no doubt in my own mind that the politics and public opinion was far ahead of many experts' expectations.'[90] Opt-out law reform was more than a simple artefact of abstract ethics or policy innovation. Rather, it gave expression to a territorialized identity rooted in values already familiar from Morgan's 'clear red water' speech, as previously discussed.

By contrast, there were considerably fewer express references to distinctive traits in the other three countries. This was perhaps surprising in the case of Scotland, given that the reforms followed closely in the wake of the 2014 independence referendum. There was also an absence of positive claims regarding identity in Northern Ireland and opt-out law reform. Indeed, rather than confirming singular values there, reference was more often made to campaigners and legislators temporarily drawing opposing sides together. This was highlighted in relation to the approach taken by Dáithí Mac Gabhann and his parents as they campaigned for opt-out:

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[84] Parsons, op. cit., n. 3.

[85] BBC News, 'Hart: Opt-Out Organ Donation Plan "No Burden for NHS"' *BBC News*, 20 January 2011, at <https://www.bbc.co.uk/news/uk-wales-politics-12240622>.

[86] Participant 4.

[87] See further E. Stokes and C. Smyth, 'Hope-Bearing Legislation? The Well-Being of Future Generations (Wales) Act 2015' (2024) 13 *Transnational Environmental Law* 569.

[88] Participant 20.

[89] Id.

[90] Participant 15.

> For a five year old to go out there and play the room the way he plays the room is … brilliant to see and he went right across all political parties, he had them all eating out of his hand. Which, for Northern Ireland is quite a trick![91]

For Westminster lawmakers, the position was somewhat different. They were more concerned about libertarian anxieties with respect to 'telling people what to do',[92] along with a desire to make clear to the public that 'organs were still the property of the individual and it wasn't the state taking control of those organs'.[93] This preoccupation with the 'nanny state' appeared to be more common in English political discourse than elsewhere in the UK.[94] However, if paternalism and coercion was 'just not how this country works',[95] the 'country' in question was not named. Indeed, several English participants expressly denied that there was an affirmatively 'English' dimension to the new opt-out legislative regime.[96] When specific traits were explicitly referenced, this was done in a more self-deprecating vein than in Wales. Thus, England, or at least parts of it, were regretfully stated to be

> a society that takes a utilitarian approach, rather than a social cohesion and social responsibility approach … And that sort of social pressure to so-called 'do well', that's there. Which means that we don't put as much value on the non-financial aspects of things, such as interpersonal relationships and supporting each other.[97]

Given this perceived deficiency, it was considered that the introduction of opt-out would have a meliorative effect, fostering 'the community and cooperative spirit of looking out for others'.[98]

British values were also rarely denominated as such. Even when they were, this was in a minor key across all four countries, with references to a typical 'squeamishness' in relation to end-of-life issues,[99] or 'a certain Britishness around doing the right thing',[100] for example, rather than a declamatory linking of positive values to the territory of the UK. Rather, participants highlighted a shared sense of caution, contrasted with approaches assumed to be taken in other states, with one observing that

> [t]he Spanish system … goes much, much further than we have in any of the nations in the UK … [T]hey harvest the organs and see if there's a use for them after. That culturally works in Spain – I don't think it would work here at all.[101]

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[91] Participant 11.

[92] Participant 25.

[93] Participant 18.

[94] Participant 11. See further McEwen, op. cit., n. 16, p. 84.

[95] Participant 25.

[96] This rhetorical self-effacement echoes an earlier imperial nationalism, which posited Englishness as uniquely aligned with universal values: see further P. Fitzpatrick, *Modernism and the Grounds of Law* (2001) 121.

[97] Participant 20.

[98] Participant 25.

[99] Id.

[100] Participant 17.

[101] Participant 6.

While salient in signalling self-perceptions common to all UK countries, this overlooked the fact that Spain does not take such a 'hard' approach to opt-out in practice.[102]

8 | THE IMPORTANCE OF THE GIFT

For Titmuss, the territoriality of the altruistic tissue donation system was closely aligned with that of the whole UK, a link made concrete by the institutional design of the NHS. Opt-out reforms to that system were made possible by devolution, which had itself followed on the perceived repudiation by Conservative governments of the territorial and class bargain embodied in the post-war welfare state. However, the findings from our empirical research do not show a consistent reterritorialization with reference to the specific countries of the UK as regards representation or values. Apart from Wales, as we have seen, the change was not seen as directly expressing a distinct ethos or as flagging exemplarity at sub-state level. What the findings do reveal is the salience – indeed, the centrality in opt-out reform – of altruistic organ donation, both at Westminster and among the devolved governments. In this section, we examine how that position was affirmed and the manner in which key elements of Titmuss' case for non-commercial donation were rearticulated in light of the shift from opt-in to opt-out. These involved defending the non-coercive nature of the new system, justifying it in terms of waste avoidance, and building on relationships to promote donation.

8.1 | 'Ensuring that the gift is preserved': the opt-out paradox

Previous attempts at reform had foundered on the objections of a range of interested groups, and reformers sought to address these concerns. Among healthcare professionals, particularly those working in the area of organ transplantation, there was a fear 'that people would say "They're taking my organs, I'm going to opt out" and massive numbers would opt out . . . actually [making] the system worse'.[103] The Burke and Hare medical body-snatching scandal in nineteenth-century Scotland was explicitly evoked as a warning in this regard.[104] Lawmakers thus recognized that 'if the clinical community spoke up publicly against you, you would lose the public'.[105] These pragmatic considerations were reinforced by the need to consider the moral objections of many religious groups, including the fear that opt-out reforms would lead to state control of the body, and the risk that 'opting out [would] . . . erode the giving aspect of donation'.[106] As one lawmaker put it, '[y]ou can't sound like you as a politician are telling people what to do. It's not the army. [You] can't go around ordering people to go out for a run or [not to] eat too many doughnuts.'[107]

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[102] See C. J. Rudge, 'Editorial: Organ Donation: Opting In or Opting Out?' (2018) 68 *Brit. J. of General Practice* 62.

[103] Participant 21. This is widely confirmed: see for example Royal College of Surgeons, *Position Statement: Opt-Out Consent for Organ Donation* (2019), at <https://www.rcseng.ac.uk/-/media/files/rcs/about-rcs/government-relations-consultation/rcs-position-paper-on-organ-donation-january-2019.pdf>.

[104] Participant 7.

[105] Participant 15.

[106] Participant 5.

[107] Participant 25.

Advocates of opt-out met these concerns by framing the gift in terms of what we might call the 'opt-out paradox'. Accordingly, rather than removing choice by presuming consent (or 'authorisation'), the legislation was 'actually seeking … to ensure that the gift is preserved'.[108] This assertion was supported in four main ways. First, the legislation would actually allow individuals to make a clear and categorical decision explicitly to opt-in or to opt-out. Second, religious and ethical perspectives were discounted to a degree. Objections from the Anglican Church in Wales, for example, were met with mild scepticism by proponents of the legislation. As one observed, '[t]here was no real way of reconciling the two positions. They made their appeal, we listened, but that's not where we were as a government … [Y]ou can only present the facts and let people have their religious beliefs.'[109] Northern Ireland was an exception insofar as there was 'evidence to show that out of the whole of the UK [it] is a much more religious place', requiring reassurance from proponents of reform that 'people's faiths and beliefs … would be respected and taken into consideration'.[110] Nonetheless, even there, outright objections to opt-out were not allowed to prevail. Equally, a submission to the UK government from the Nuffield Council on Bioethics, querying evidence that opt-out would increase donation rates in England, was accorded less significance than media campaigns in favour of change featuring individual stories such as those of Max and Keira, or Dáithí Mac Gabhann. Third, individual medical professionals and their representative organizations were widely included in consultations, as well as in policy design.[111] Fourth, polling data showing public support for donation in general was taken to extend to the specific features of the new regime. As one participant put it, '[o]ver 90 percent of people would donate an organ if they could … So this "soft" opt-out system … better reflects that public opinion.'[112] Accordingly, reform was seen as being 'driven by the public rather than us taking the public along',[113] with the shift in parliamentarians' views a result of 'the way society has moved'.[114] These findings also allayed fears of mass opt-out caused by a perceived loss of autonomy and the over-extension of state control.

8.2 | 'A massive difference': the efficient gift

Participants emphasized the capacity of opt-out to save or transform lives as a motivating force for reform. Even though it was recognized that 'legislation on its own wasn't going to completely solve all the issues',[115] the goal of increasing the number of organs available for transplant was widely articulated and in a distinctly utilitarian idiom. First, as provided for in the Welsh, Scottish, and Northern Irish legislation, publicity campaigns relating to the new system would raise public awareness, encouraging more individuals to register affirmatively as potential donors, adding to those included by way of the opt-out mechanism itself. Second, opt-out would avoid organs going unused for lack of positive consent or clarity about the wishes of the deceased individual. Third,

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[108] Participant 7.

[109] Participant 13.

[110] Participant 9.

[111] Id.

[112] Id.

[113] Participant 3.

[114] Participant 6.

[115] Participant 11.

subject to the express exclusion of certain organs as set out in the new legislative regimes, it was expected that a range of organs could be made more readily available for transplant to recipients from a single post-mortem donation:

> [Y]ou can take theoretically more than one organ from an individual – I mean it can be up to sort of seven or eight … [F]or example, very old people can give their eyes, and very old people can give their skin for research.[116]

Fourth, memoranda concerning the new legislative regimes also mentioned likely further gains, such as reduced pressure on the NHS, lower expenditure on procedures such as kidney dialysis, and the ability of an individual with an organ transplant to return to gainful employment and to support the economy.[117] By contrast, one participant noted that the notional price to be paid for these gains was relatively low.[118] After all, deceased organ donation, while morally significant, is not burdensome or intrusive in the same way as living donation.[119] Indeed, this notion of efficiency was extended to the mode of law reform itself, which 'provided the opportunity to save lives with what was a very minor change of the legislation'.[120] Given the low 'cost' involved, it was considered right for deceased individuals whose views were not known 'to be used to save lives rather than just being buried, or burned, or something'.[121] Ultimately, unproductive waste was problematized by this utility calculus, with opt-out reforms being proposed as a means of avoiding it and allowing stewardship of valuable resources that would save lives.

8.3 | 'Part of the gifting process': families and conversations

Law- and policymakers recognized that 'family support was always going to be an important part' of gifting as promoted by the reforms.[122] Indeed, the role of relatives and loved ones at the time of deceased organ donation was specifically problematized in light of the claim that they were vetoing organ donation by deceased family members.[123] The introduction of 'hard' opt-out schemes would have formally eliminated this veto, but that would likely have proved unpopular with the general public and medical professionals.[124] By contrast, 'soft' opt-out, which was ultimately adopted across the UK, affords relatives (and some others)[125] a significant role in providing information, though not in formal decision making. These rules are expected to promote organ

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[116] Participant 17.

[117] See for example Human Tissue (Authorisation) (Scotland) Bill, Policy Memorandum, SP Bill 32-PM Session 5 2018, 8 June.

[118] Participant 6.

[119] See further B. Venter, 'Thinking Carefully about Organ Donation: Janet Radcliffe-Richards' *The Ethics of Transplants: Why Careless Thought Costs Lives*' in *Leading Works in Health Law and Ethics*, eds S. Fovargue and C. Purshouse (2023) 211.

[120] Participant 25.

[121] Participant 21.

[122] Participant 2.

[123] Participant 7.

[124] Participant 13.

[125] This includes close friends in Wales, and all others in Scotland: see above text to n. 59.

donation by ‘changing the angle of the conversation’ between families and healthcare professionals, rather than by allocating or reallocating a power of veto.[126] As such, opt-out reforms are seen as being more consistent with the UK’s traditionally altruistic approach to donation, with one participant observing that they would bring ‘relatives into a position where they are part of the gifting process as well’.[127] At the same time, another participant noted that by registering their wishes, individuals could ‘take the pressure off their family’ at a time of distress.[128]

Intra-familial conversations, specifically during the lifetime of the individual, were also considered necessary, but currently deficient links in achieving increased organ donation. It was hoped that the future prospect of deemed consent (or ‘authorisation’) for deceased organ donation would encourage family members to state and discuss their wishes in the present. This would ensure that donation became a ‘normalized subject in society’.[129] Gendered understandings of family life proved to be significant in this regard. Thus, when asked who influences decisions, survey respondents in Wales were reported to have said that

> [i]t was the mother of the family … [I]f they want to say ‘No, this is rubbish’, the family would say ‘Yeah, we’ll listen to mum here … You know, if you want to have a conversation, let’s talk about organ donation over your beans.’

This feedback led to further targeted consultations with women’s groups.[130] The association of families with the promotion of altruism in society also registered with persuasive effect during campaigning for legislative change. While the cases of identified patients receiving or in need of organ transplants were vital in ‘crystallizing the issues’ at hand,[131] these individuals were also perceived to be speaking in unison with their families. Thus, Dáithí Mac Gabhann and his parents impressed lawmakers by testifying ‘so compassionately about what other people are going through – it’s just a whole other world’,[132] while ‘you could not have had a stronger argument from a better family in many ways [than those of Max and Keira], and that’s what turned it, I think’.[133]

9 | DISCUSSION

We began this article by questioning whether the relationship between values, territory, and health law had changed since devolution in the UK. In response, we have presented findings from our empirical research on opt-out organ donation law reform informed by theoretical perspectives from human geography and policy studies. We asked first to what extent territorial arrangements were significant for the content of health law and the normative standards by which it is oriented. As regards this specific but high-profile and politically sensitive area of health policy, it is obvious that four formally distinct legislative regimes now govern deceased organ donation. It is also clear,

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[126] Participant 11.

[127] Participant 13.

[128] Participant 10.

[129] Id.

[130] Participant 15.

[131] Participant 7.

[132] Id.

[133] Id.

however, that these regimes overlap considerably in substance. Subject to variable limitations in detail, which we have previously noted, a common opt-out organ donation regime is now in force across the UK. Many of our participants expressed satisfaction that broad consistency had been achieved. Most confirmed that this outcome had resulted from ‘policy transfer’ – a process of learning, emulation, and adaptation between the four governments and administrations, whether publicly acknowledged at the time or not.[134] That process was the more intense given established contacts between civil servants, the willingness of politicians involved to advise peers elsewhere, and the ‘horizontal transmission’ of technical information and experience by institutional and professional organizations such as NHSBT and the BMA.[135]

Policy transfer from country to country presupposes and confirms the division of the UK into separate legal and administrative zones. However, it also highlights the frequency and readiness with which these borders are crossed. Participants indicated an awareness of the potential for one country – in this case, Wales – to function as a ‘policy laboratory’ in the manner predicted by scholars of devolution.[136] As regards the development and content of relevant law, then, the healthcare system in the UK has indeed been reterritorialized, but not sundered – far from it. Polemical references in the media to ‘medical apartheid’[137] post-devolution are well wide of the mark. Rather, things are somewhat messier, as cross-UK agencies of varying functional and geographic remit interact with devolved institutions and a range of non-governmental bodies. The change in this regard is less remarkable if we recall that the UK has never been a single homogeneous space, with Westminster as the single point of reference for health policy and practice. The distinction drawn by historians and political scientists between a unitary state and a union state expresses this difference well.[138] As we have noted, nominal centralization within the NHS during the post-war decades was undercut by local variety and considerable professional discretion. This effect was compounded by administrative devolution to the Scottish and Welsh Offices, from 1948 and 1965 respectively, and formal devolution to Northern Ireland between 1921 and 1972. In reality, the territoriality of health and welfare was already pluralistic rather than unitary prior to 1998. Devolution has changed important elements of that order, influencing both the content of health law and how and where it is made – but the underlying pluralism remains.

Territoriality is not simply an objective dimension of administrative and legislative competence, however. It is realized discursively through representations linked to given spaces. Accepting this allows us to address our second question regarding the role played by devolved health law in redefining territories and identities within the UK. Findings from our empirical research show that, as with legal and institutional developments and reform processes, this dimension was also marked by pluralism rather than singularity. At a general level, we did find a common awareness of border issues and the need to learn from elsewhere, as well as a certain sensibility for distinct values. However, these differed considerably as regards intensity and concrete focus, each being influenced by local histories and contemporary concerns. Thus,

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[134] D. Dolowitz and D. Marsh, ‘Learning from Abroad: The Role of Policy Transfer in Contemporary Policy-Making’ (2000) 13 *Governance* 5.

[135] Keating et al., op. cit., n. 5, p. 64.

[136] See for example A. Paun et al., *Devolution as a Policy Laboratory: Evidence Sharing between the UK’s Four Governments* (2016).

[137] See S. L. Greer, ‘Devolution and Health Policy in the UK’ (2008) 14 *Eurohealth* 22.

[138] See J. Mitchell, ‘Evolution and Devolution: Citizenship, Institutions, and Public Policy’ (2006) 36 *Publius: The J. of Federalism* 153; A. McHarg, ‘Unity and Diversity in the United Kingdom’s Territorial Constitution’ in *The Unity of Public Law? Doctrinal, Theoretical and Comparative Perspectives*, eds M. Elliott et al. (2018) 279.

the border between Northern Ireland and the Republic of Ireland raised issues about external access to the NHS, while the border between England and Wales was the focus for concerns about harmonious standards within the UK. Evident pride in Cardiff's position as first mover on opt-out reform echoed the recurrent trope among political leaders that the NHS is Wales' gift to the rest of the UK. By contrast, Northern Ireland's place as last in the sequence of implemented opt-out reforms generated familiar anxiety in the policy community there about a loss of parity, as well as resonating with enduring concerns among Unionist politicians about being left behind by the rest of the UK.[139] Thinking at Westminster was marked by ostensible indifference to developments elsewhere, combined with apprehension about divergence within the UK, and ultimately a willingness to learn even if unacknowledged. As Michael Kenny has recently argued, this unstable mix reproduces the historic tendency of Westminster to 'devolve and forget', alongside a persistent fear that the state will lose control over its geographical periphery, and a silent pragmatism in some cases.[140] Each country example confirms the dynamic and relational nature of territoriality, with one social order defined spatially through its connections to and differences from others. Health law developments, such as the shift to opt-out, provide the occasion for reiterating but also adapting these territorial connections and differences.

Values combine with representations and institutions in the production of territoriality. In this regard, our research highlights the enduring relevance of altruism as an ethical orientation for organ donation law and practice across the UK. Indeed, while a range of substantive values was mentioned by participants, the concept of the gift was by far the most frequently utilized to define the purpose of legislation and to explain its purpose.[141] Reformers treated it in effect as an 'obligatory point of passage',[142] a key commitment with which opt-out law reform had to be expressly aligned in order to be defensible vis-à-vis opponents and the general public. Three important aspects of Titmuss' original conception concerning the gift relationship were evident from the data, albeit reshaped for the distinct context of opt-out. Non-coercion would be ensured through the figure of the opt-out paradox, which portrayed the reforms as bolstering rather than undermining the autonomy of organ donors. Waste would be avoided by a simple measure of law reform facilitating increased procurement of organs from deceased organ donors whose true wishes had been frustrated by the earlier opt-in legislative regime. Relationships, notably between family members, would be reinforced and mobilized towards the greater social goal of saving lives. It should be emphasized that the priority accorded to non-commodified donation and the three dimensions identified here were a feature of the reform process in all four countries.

Notwithstanding some identification of Wales with community spirit and altruism, legislators and campaigners alike affirmed that 'socially we're not all that different',[143] with the consequence that the reforms 'could easily have originated in Scotland or anywhere else for that matter'.[144] This sense of social similarity, underpinned by a common ethos, contrasts with the strong claims of distinctiveness made in the run-up to devolution in 1998 and subsequently. However, if the gift

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[139] See comments of James Craig, first Prime Minister of Northern Ireland, in 1929, quoted in Simpson, op. cit., n. 11, p. 137.

[140] M. Kenny, *Fractured Union: Politics, Sovereignty and the Fight to Save the UK* (2024) 130.

[141] The other values identified in the data were altruism, compassion, natural justice, non-coercion, trust, respect for beliefs, transparency, autonomy, public support, cooperation, community, families and relationships, liberty, social cohesion, social duty, caring, and virtue.

[142] See M. Callon, 'Elements of a Sociology of Translation: Domestication of the Scallops and the Fishermen of St. Brieuc Bay' in *Power, Action and Belief: A New Sociology of Knowledge?,* ed. J. Law (1986) 196.

[143] Participant 7.

[144] Participant 13.

was not mapped to the territories of the different countries, neither was it explicitly marked as 'British'. Titmuss had linked altruistic human tissue donation with the NHS and the UK state, a territorializing move reprised by former Prime Minister Gordon Brown, who claimed that the NHS is a 'very British expression of an ideal – that healthcare is not a privilege to be purchased but a moral right secured for all'.[145] Indeed, the Commission on the UK's Future, which he chaired, recently reiterated this view of consciously shared values and institutional commitments, along with a proposal for interterritorial solidarity, in relation to healthcare.[146] Given the capacity of organ donation to 'include the citizen in the fate of the nation',[147] opt-out reform would seem to have provided an opportunity for further promoting this ideal of civic Britishness, at least at Westminster.[148] However, we found no evidence for this in data from our empirical research.

10 | CONCLUSION

In this article, we have shown that opt-out organ donation law reform was not explicitly aligned with the territoriality of the UK's devolved countries or that of the state as a whole, as regards institutions, representations, and values. The gift was also not deployed to define identity at any level in the UK. Instead, we suggest that it functions as a shared – though not a singular – horizon for health law, a 'soft' factor facilitating policy transfer in this area.[149] The purchase of the gift is derived historically from the shared origins of each of the four health services in a unified NHS and the decommodified form of healthcare delivery inaugurated in 1948, as defended in Titmuss' *The Gift Relationship*. It is reinforced in the present day by the continued integration of certain key activities across England, Northern Ireland, Scotland, and Wales, including organ transplantation, delivered through shared infrastructure. UK-wide institutions, professional networks, and non-governmental organizations are guided by such values, and play an important role in ensuring the continued acceptance of those values among politicians, policymakers, and the wider public. This ensemble is underpinned by a pragmatic desire on the part of all involved in developing the opt-out reforms to ensure that suitable 'organs could be used wherever' in the UK they were needed.[150] This is evidenced by asymmetric rules, which include only residents as opt-in donors but provide for the distribution of organs across all four countries. Opt-out reforms reproduce a common space of shared values and policy learning, marked by institutional pluralism – one that is largely uncoupled from controversies over devolution in the UK. Finally, this article has confirmed that territory is not simply an inert dimension of law under devolution or more generally. As such, it highlights the potential for theoretically informed, empirical socio-legal research to document the influence of spatial thinking on developments in health law and policy, and the contribution of legal change to territorialization and reterritorialization.[151]

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[145] G. Brown, 'In Full: Brown Speech on the NHS' *BBC News*, 7 January 2008, at <https://news.bbc.co.uk/1/hi/uk_politics/7175083.stm>.

[146] Commission on the UK's Future, *A New Britain: Renewing Our Democracy and Rebuilding Our Economy* (2022) 45, 67, 70, at <https://labour.org.uk/wp-content/uploads/2022/12/Commission-on-the-UKs-Future.pdf>.

[147] See Waldby and Mitchell, op. cit., n. 8, p. 20.

[148] See Kenny, op. cit., n. 140, p. 72.

[149] D. Benson and A. Jordan, 'What Have We Learned from Policy Transfer Research? Dolowitz and Marsh Revisited' (2011) 9 *Political Studies Rev*. 366.

[150] Participant 6.

[151] See further J. Harrington, *Towards a Rhetoric of Medical Law* (2017) ch. 3.

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