


The Connection–Friction Axis in Devolved Health Policy and Law-Making in the UK: A Case Study of Organ Donation

Ruby Reed-Berendt,^{*}  Anne-Maree Farrell,[†]
Matthew Watkins[‡] and John Harrington[§]

This article explores the dynamics of devolved health policy and law-making in the UK, drawing on a case study of opt-out organ donation reform. Given that health is a significant area of devolved competence, such case studies offer the opportunity to examine both similarities and differences in approach between the four nations in the context of the UK's evolving constitutional settlement. We argue that there is a need to move away from the characterisation of the devolved health policy-making process as being grounded in a convergence–divergence approach, towards one that recognises the connection–friction axis around which this process takes place. To explore this, we present findings from empirical research on opt-out organ donation law reform. This, we suggest, demonstrates that whilst connectedness between government stakeholders, experts and advocacy groups was clearly vital in structuring the policy process, account should also be taken of how law operates not only as a medium for the playing out of political and ideological friction, but also for the achievement of connection to overcome this.

INTRODUCTION

In recent years, organ donation law reform has been high on the political agenda in the United Kingdom (UK). Against a background of ongoing concerns about the need to increase the supply of organs from deceased donors to meet demand,¹ legislative reform has taken place in each of the

^{*}Research Associate, School of Law, University of Edinburgh.

[†]Chair of Medical Jurisprudence, School of Law, University of Edinburgh.

[‡]Lecturer in Healthcare and Family Law, Department of Humanities and Law, Bournemouth University. This author would like to thank the ESRC for allowing him time to collect data and contribute to this publication during his Fellowship.

[§]Professor of Global Health Law, School of Law & Politics, Cardiff University. Research for this paper was undertaken as part of the project, 'Legal Transplants and Policy Transfers: Legislating for Organ Donation in a Devolved UK' (SRG21/210396), which was funded by the British Academy and The Leverhulme Trust. The authors gratefully acknowledge their support. The authors are also grateful for the constructive feedback on an early draft of this paper received from attendees at the workshop 'Legal Transplants and Policy Transfers: Health Law in a Devolved UK', which took place at Cardiff University Law School on 15 September 2023.

1 Laura Donnelly, 'Heart Transplant Waiting Lists Reach Record High, with Doubling in Number Waiting' *The Telegraph* 24 September 2019 at <https://www.telegraph.co.uk/news/2019/09/23/heart-transplant-waiting-lists-reach-record-high-doubling-number/> [<https://perma.cc/3Q92-29U9>]; Nicola Davis, 'All Adults in England to Be Deemed Organ

UK's four nations in the past 10 years.² This has culminated in the adoption of what are commonly known as 'opt-out' regimes for organ donation across the UK; a marked shift from previous approaches based on informed consent/authorisation.³ Under these regimes, individuals are presumed to have consented to, or authorised, the use of their organs for donation after death. The presumption may be overturned if during their lifetime the person recorded their objection to donating via the national organ donor register, or otherwise made their objection clear, for example to family or friends.⁴ This marks a departure from previous approaches to increasing rates of deceased organ donation, which focused on institutional and clinical services reform within and across the UK's four health systems (collectively referred to as the National Health Service (NHS)).⁵ Accordingly, this represents a significant policy shift towards the use of law as the preferred policy mechanism to address the demand and supply problem in organ donation.

Drawing on findings from qualitative empirical research, in this article we examine the process of opt-out organ donation reform as a case study to analyse the broader dynamics of health policy and law-making in a devolved UK. Critical reflection on such dynamics should be seen as a vital adjunct to the more established law and ethics analyses that have characterised the examination of this topic in the health law literature to date.⁶ Moreover, a focus on these dynamics

Donors in "opt-out" System' *The Guardian* 19 May 2020 at <https://www.theguardian.com/society/2020/may/19/deceased-uk-adults-to-be-deemed-organ-donors-in-opt-out-system> [<https://perma.cc/58KQ-8HKR>]; James MacKinnon, 'Scotland's Organ Donation Law Is Changing to an Opt-out System and We Should Make Sure Our Wishes Are Heard' *The Scotsman* 7 March 2021 at <https://www.scotsman.com/news/opinion/columnists/scotlands-organ-donation-law-is-changing-to-an-opt-out-system-and-we-should-make-sure-our-wishes-are-heard-james-mackinnon-3151729> [<https://perma.cc/6P5D-689Z>]; Emma Montgomery, 'Dáithí's Law: MPs' Backing Welcomed but MLA Says Stormont "Shouldn't Need Westminster to Do Its Job"' *Belfast Telegraph* 22 February 2023 at <https://www.belfasttelegraph.co.uk/news/politics/draithis-law-mps-backing-welcomed-but-mla-says-stormont-shouldnt-need-westminster-to-do-its-job/392191791.html> [<https://perma.cc/S3ZZ-VHR6>].

- 2 For the purposes of this article, we use the term 'nation' to delineate between England, Northern Ireland, Scotland, and Wales. In doing so, we make no claim to be drawing on formal political science understandings of the term, see for example Ernest Gellner, *Nations and Nationalism; Introduction by John Breuilly* (Ithaca, NY: Cornell University Press, 2nd ed, 2008).
- 3 We utilise the umbrella term of 'opt out' to capture the deemed consent systems operating in England, Wales, and Northern Ireland, and the deemed authorisation system in Scotland. We note there are various approaches to opt out including 'soft' and 'hard' approaches. For a discussion see David P. T. Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (Cambridge: CUP, 2009) ch 5.
- 4 Human Tissue Act 2004 as amended (HTA 2004); Human Transplantation (Wales) Act 2013 (HTWA 2013); Human Tissue (Scotland) Act 2006 as amended (HTA 2006). For an overview, see Anne-Maree Farrell and Edward S. Dove, *Mason and McCall Smith's Law and Medical Ethics* (Oxford: OUP, 12th ed, 2023) ch 13.
- 5 John Fabre, 'Presumed Consent for Organ Donation: A Clinically Unnecessary and Corrupting Influence in Medicine and Politics' (2014) 14 *Clinical Medicine* 567; James Neuberger, Patrick Trotter and Ronald Stratton, 'Organ Transplantation Rates in the UK' (2017) 359 *BMJ (Online)* j5218.
- 6 Price, n 3 above; Antonia J. Cronin and James F. Douglas, 'Non-Standard Kidneys for Transplants: Clinical Margins, Medical Morality, and the Law' (2013) 21 *Med L Rev* 448; Trevor Stammers and Matt James, 'Opt-Outs and Upgrades: Ethics and Law in the United Kingdom' (2014) 23 *Cambridge Quarterly of Healthcare Ethics* 308.

enables consideration of the processes which shape health law and policy reform, making a significant contribution to existing literature which has largely focused on the role of judicial or intermediate actors.⁷ Specifically, we argue that a more nuanced analysis is now required of how policy and law-making takes place in the context of devolved (health) competence. This involves moving away from the traditional characterisation of the devolved health policy process as one grounded in convergence–divergence,⁸ towards one that takes account of the *connection–friction* axis around which this process takes place. Our novel account recognises the importance of *connection* between policymakers and stakeholders in addressing areas of similarity and difference, and how this is central to managing *friction* within and between the UK nations that may arise in policy and law-making processes.

We use the term *connection* to examine the ways in which actors, institutions – and indeed the devolved nations – relate to and connect with one another in the policy process. The UK’s devolution model – and the distinct devolution settlements within it – has created various connections between the nations, with implications for (devolved) health policy and law-making.⁹ First, connections between institutions such as the NHS or UK-wide stakeholders mean that certain organisations retain their importance and influence in all the four nations; these connections can generate political impetus to create a single workable system. Political connections in the health sector often mean that policymaking does not happen in isolation, with policymakers looking to activities in other UK nations to shape their own responses. Moreover, a shared sense of values creates connections between the nations and are an important locus for policy development and alignment.¹⁰

We use the term *friction* to denote resistance or challenges which arise as actors, institutions, and political leaders navigate the health policy process. How this is manifested may vary, depending on the specific context, as well as the actors and institutions engaged in policymaking. For example, resistance may arise from actors or publics in opposition to a potential policy; conversely, a challenge to a given policy or law reform process could take place at a political level – with different political parties, politicians, or governments taking conflicting stances on an issue. It is also important to take account of how friction arises at a constitutional level, as governments in the devolved nations exercise their competences. This may culminate in uncertainty or disagreement within and between nations over the extent of devolved competence, exemplified by constitutional challenges in the UK courts surrounding the limits of devolved

7 Jonathan Montgomery, Caroline Jones and Hazel Biggs, ‘Hidden Law-Making in the Province of Medical Jurisprudence’ (2014) 77 MLR 343.

8 Scott L. Greer, ‘The Territorial Bases of Health Policymaking in the UK after Devolution’ (2005) 15 *Regional & Federal Studies* 501.

9 Department for Levelling Up, Housing and Communities and Cabinet Office, ‘Devolution: Scotland, Wales and Northern Ireland’ (Collection, 16 May 2023) at <https://www.gov.uk/government/collections/devolution-scotland-wales-and-northern-ireland> [<https://perma.cc/PLA8-4W8Q>].

10 John Harrington, Barbara Hughes-Moore and Erin Thomas, ‘Towards a Welsh Health Law: Devolution, Divergence and Values’ (2021) 72 NILQ 62.

powers.¹¹ In considering how these two concepts relate to one another, making use of connections to respond to or manage episodes of friction appears to be crucial to enable the adoption of a policy. Moreover, law can operate as a medium for the playing out of friction and the achievement of connection to overcome this, especially in the context of politically or ethically sensitive issues.¹²

In this article, we first provide a brief overview of our research methodology and the UK devolution settlement. We then discuss key frameworks in the literature which have been used to analyse devolved policymaking, namely convergence–divergence, and Kingdon’s model of ‘policy windows’.¹³ Whilst Kingdon’s model, with its ability to consider the need for alignment of numerous conditions to allow policy change, provides a useful lens to consider the nuances of devolved health policy and law-making, we suggest that it can be augmented by taking into account our novel connection–friction approach. This allows us to better grapple with the unique dynamics of devolved health policy and law-making, in the context of the evolving constitutional settlement in the UK.

We then turn to our case-study of opt-out organ donation law reform. After summarising the legislative processes which led to the adoption of deemed consent/authorisation legislation in the four nations, we identify the composition of each of the three streams in line with Kingdon’s model, using this to highlight instances of connection and friction. We analyse the unique ways in which the streams came together in Wales, Scotland, England, and Northern Ireland to facilitate the legislative shift to opt-out organ donation, arguing that in each case, instances of friction had to be navigated and mitigated by making use of connections both within and across the UK nations. We conclude by considering the broader implications arising from the case study for devolved health policy and law-making in the UK.

METHODOLOGY

In undertaking this analysis, we draw on both normative and qualitative empirical research. This consisted of both documentary analysis and semi-structured interviews with key individuals involved in the process of organ donation law reform. We explored the political and legislative processes surrounding the adoption of opt-out regimes for organ donation to provide a detailed case study

11 See for example *REFERENCE by the Attorney General and the Advocate General for Scotland – United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill*; *REFERENCE by the Attorney General and the Advocate General for Scotland – European Charter of Local Self Government (Incorporation) (Scotland) Bill* [2021] UKSC 42; *R (on the application of the Counsel General for Wales) (Appellant) v Secretary of State for Business, Energy and Industrial Strategy (Respondent)* [2022] EWCA Civ 118 (application to appeal refused on 9 August 2022, UKSC 2022/0055).

12 We adopt a definition of law that fits broadly within the socio-legal tradition, see for example David Cowan and Daniel Wincott (eds), *Exploring the ‘Legal’ in Socio-Legal Studies* (Basingstoke: Palgrave Macmillan, 2016); Naomi Creutzfeldt, Marc Mason and Kirsten McConnachie (eds), *Routledge Handbook of Socio-Legal Theory and Methods* (London: Routledge, 2019).

13 John W. Kingdon, *Agendas, Alternatives, and Public Policies* (Harlow: Pearson, 2nd ed, 2014).

on the making of devolved health policy and law-making across the UK. Approval to conduct this research was granted by Cardiff University School of Law Research Ethics Committee (SREC-211103-02).

We began with a literature 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 nation who were then invited to participate in an interview. Other potential participants were identified in a 'rolling process' through recommendations from interviewees. A total of 26 participants were interviewed: four in Scotland, four in Northern Ireland, eight in Wales, nine in England, and one who had been involved across the four nations. Participants included 10 politicians, six civil servants, six activist groups and individuals, one media representative, and three members of NHS staff. Interviews took place between 27 January and 26 August 2022 and lasted between 25 and 110 minutes 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, who they were in contact with, and the key values 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.¹⁴ Transcripts were coded independently, with a comparison of 10 transcripts to ensure consistency and to identify emerging themes. To preserve anonymity, each participant is referred to in this paper only by participant number.

In conducting qualitative empirical research, we recognise that there are limitations to this work, given that we are drawing on findings from a limited sample of interviewees holding specialised policy and clinical expertise, and/or advocacy experience, who have specific perspectives.¹⁵ However, this area of health policy and law is significantly under-researched in the UK. In the circumstances, we consider the findings have the potential to generate 'theoretical generalisability',¹⁶ in that they can offer broader insights into, or hypotheses about, the changing dynamics of devolved health policy and law-making as part of evolving constitutional arrangements in the UK.

DEVOLUTION AND HEALTH COMPETENCE

As a devolved entity, the UK has four distinct legislatures and executive bodies. The UK government and parliament are based in Westminster in London;

14 Virginia Braun and Victoria Clarke, *Thematic Analysis: A Practical Guide* (Los Angeles, CA: SAGE, 2022); Greg Guest, Kathleen M. MacQueen and Emily E. Namey, *Applied Thematic Analysis* (Los Angeles, CA: SAGE, 2012).

15 In this regard, we recognise the tension in the conduct and use of findings from qualitative empirical research between the particular and the generalisable, see for example *ibid*; Lara Carminati, 'Generalizability in Qualitative Research: A Tale of Two Traditions' (2018) 28 *Qual Health Res* 2094.

16 Jennifer Mason, *Qualitative Researching* (Los Angeles, CA: SAGE, 3rd ed, 2017).

however, legislative powers have been devolved to Scotland, Wales, and Northern Ireland in certain areas.¹⁷ Because health is a devolved matter in Scotland and Wales,¹⁸ and a transferred matter in Northern Ireland,¹⁹ health legislation passed by the UK parliament is, generally, only applicable to England.²⁰ Each of the devolved administrations operates under a specific devolution settlement, with distinct parliamentary systems, political parties, and law-making powers. A brief summary of these is provided below.

The devolved legislature in Scotland, the Scottish parliament (Holyrood),²¹ operates under a reserved model of devolution. Holyrood has primary law-making power for legislation over all matters (including ‘health’), except those explicitly reserved to the central UK government.²² The Scottish government has been led by the pro-independence Scottish National Party (SNP) since the 2007 Scottish parliamentary elections.²³ By contrast, the powers of Welsh devolved legislature, initially known as the National Assembly for Wales,²⁴ have evolved over time. At first the Welsh Assembly had no primary legislative powers and could only make legislation in a limited range of areas, including health.²⁵ During this time, the Welsh Assembly could request powers to pass legislation via a Legislative Competence Order (LCO) from Westminster.²⁶ In 2011 the Welsh Assembly was granted primary law-making powers (however, still in relation to limited matters that had been conferred).²⁷ In 2017 Wales

17 Although there have been recent devolution initiatives, England is the only nation without its own devolved legislature. For further discussion see Scott L. Greer, ‘Devolution and Health in the UK: Policy and Lessons Since 1998’ (2016) 118 *Br Med Bull* 16; Farrell and Dove, n 4 above, 67–68.

18 Scotland Act 1998, Sched 5, Head J; Wales Act 2017, Sched 7A.

19 Northern Ireland Act 1998, ss 4 and 6.

20 With some exceptions; for example, the Coronavirus Act 2020 applied across the UK, although it was subsequently replaced by legislation specific to each of the relevant nations.

21 Established in its current form under the Scotland Act 1998, s 1.

22 Although under the Sewel Convention and Memorandum of Understanding between the UK and devolved governments, the UK government should not normally interfere with devolved policy, or create law to override or reverse devolved legislation, the UK government continues to hold power to veto Acts of the Scottish Parliament, see Scotland Act 1998, s 35; Akash Paun and others, ‘The Sewel Convention’ (Institute for Government, 16 January 2018) at <https://www.instituteforgovernment.org.uk/explainer/sewel-convention> [<https://perma.cc/B3PM-TYYH>].

23 During this time the SNP has been in power as a majority government, minority government, and as part of a power-sharing arrangement with the pro-independence Scottish Greens. Gregory Baldi, ‘Politics without Society: Explaining the Rise of the Scottish National Party’ [2022] *British Politics* 1.

24 Established per the Government of Wales Act 1998, ss 1 and 2 (now repealed), now per the Government of Wales Act 2006, Parts A1 and 1. In 2020 the Welsh Assembly was renamed ‘Senedd Cymru’ but as it was known as the Welsh Assembly during the passage of opt-out legislation, we use this terminology when discussing the Welsh legislative body.

25 Alys Thomas, *Research Briefing: Assembly Acts and the Legislative Process – A Constitution Quick Guide* Paper Number: 18-012, Research Service, National Assembly for Wales, March 2018, 1.

26 Llinos Madeley, ‘The Constitution – Legislative Competence Orders’ MRS 07/0716 (Update) (National Assembly for Wales, November 2009) at <https://senedd.wales/media/aytkg1yl/qg07-0058-english.pdf> [<https://perma.cc/9DTD-UHB7>].

27 Welsh Government, ‘“Legislative” Devolution (2007 to Present)’ (Law Wales Glossary, 18 June 2021) at <https://law.gov.wales/constitution-and-government/constitution-and-devolution/legislative-devolution-2007-present> [<https://perma.cc/VC5K-MPTF>].

moved to a reserved power model, similar to that which exists in Scotland.²⁸ Throughout this period, the Labour Party has remained in power in Wales.²⁹

Northern Ireland's political and legislative institutions were established in 1998 via the Belfast Agreement,³⁰ which helped to end 25 years of violent sectarian conflict over the constitutional status of Northern Ireland (known as 'The Troubles').³¹ The opposing positions propose that Northern Ireland should remain part of the UK ('Unionism') or be united with the Republic of Ireland ('Nationalism').³² The Northern Ireland Assembly is the legislative body, and the executive comprises a First Minister, Deputy First Minister, and Executive Ministers, who are nominated by the Assembly's political parties through the d'Hondt formula.³³ Northern Ireland's political parties remain divided by the fundamental constitutional question. The main parties designated as 'Unionist' are the Democratic Unionist Party (DUP) and Ulster Unionist Party (UUP), and the main parties designated as 'Nationalist' are Sinn Féin and the Social Democratic and Labour Party (SDLP), with the Alliance Party pursuing a more neutral position on the constitutional question.³⁴ These distinct constitutional settlements form the backdrop on which health law and policy is made, and, as we argue below, it is crucial to recognise their influence in law-making processes.

ANALYSING DEVOLVED HEALTH POLICY AND LAW-MAKING

Many of the conceptual-analytical approaches that have been employed to examine the dynamics of public policy-making processes are grounded in the political science literature. Such approaches range from exploring

28 See Wales Act 2017, s 1.

29 For two administrations, this was with support from the pro-independence Plaid Cymru party. See Martin Shipton, 'Why Has Labour Been Dominant in Wales for So Long?' *Wales Online* 19 November 2022 at <https://www.walesonline.co.uk/news/politics/why-labour-been-dominant-wales-25543138> [<https://perma.cc/Y2U6-4BJJ>].

30 Northern Ireland Act 1998, Parts I-IV; Northern Ireland Office, 'Belfast Agreement' (Policy Paper, 10 April 1998) at <https://www.gov.uk/government/publications/the-belfast-agreement> [<https://perma.cc/P26Y-Q7HV>]; Government of Ireland, Department of Foreign Affairs, 'About the Good Friday Agreement' at <https://www.ireland.ie/en/dfa/role-policies/northern-ireland/about-the-good-friday-agreement/> [<https://perma.cc/S8Z6-E5JD>].

31 Cillian McGrattan, *Northern Ireland: 1968-2008: The Politics of Entrenchment* (Basingstoke: Palgrave Macmillan, 2010).

32 For an overview, see David Mitchell, *Politics and Peace in Northern Ireland: Political Parties and the Implementation of the 1998 Agreement* (Manchester: Manchester University Press, 2015); Sarah Creighton, 'Unionism is in Crisis in Northern Ireland – and Sinn Féin is becoming an Election-Winning Machine' *The Guardian* 24 May 2023 at <https://www.theguardian.com/commentisfree/2023/may/24/unionism-crisis-in-northern-ireland-sinn-fein-election-winning-machine> [<https://perma.cc/E3MK-4XEP>].

33 Mitchell, *ibid.* The First and Deputy Ministers are nominated, respectively, by the largest party from the largest political designation, and the largest party within the second-largest political designation. Their tenures in office are also dependent on each other, as if one resigns then the other cannot continue to hold office.

34 *ibid.*

how policy transfer takes place;³⁵ the role of ideas in informing policy design;³⁶ how organised interests and expertise influence the design and outcomes of processes;³⁷ and the key role played by institutions in structuring these.³⁸ Analyses of the dynamics of UK policy-making processes have often been characterised by what is known as the convergence–divergence approach. This focuses on the similarities and differences in processes and policies in and across the UK’s four nations.³⁹ Findings from such analyses have highlighted how the dynamics of political devolution facilitated a process of policy and problem-solving over time that led to the imposition of similar solutions, resulting in convergence around an integrated territorial provision model for the healthcare services of Northern Ireland, Scotland and Wales.⁴⁰ This was in contrast to public health, for example, where a desire for policy innovation resulted in marked divergence, particularly in the area of health inequalities.⁴¹

While this approach has proved useful in explaining intended (and unintended) examples of policy convergence and variation arising from the UK’s evolving constitutional settlement, it is limited in conceptual–analytical terms for exploring the nuanced dynamics of devolved health policy processes. Indeed, focusing exclusively on elements of convergence or divergence in legislation risks missing important facets of health policy and law-making processes in each of the UK’s four nations – including how actors navigate such processes to facilitate the passage of legislation and the impact of the devolution settlement in question. Such details are crucial when explaining not only how a policy comes to be adopted but also how we should account for policy design and outcomes, and why convergence or divergence takes place.

In the circumstances, we propose a novel conceptual approach: the connection–friction axis (as defined in the Introduction). We suggest this paradigm enables a deeper understanding of health policy and law-making processes in the UK, by recognising the dynamic links and influences within and across the four nations. Our analysis of these processes draws on Kingdon’s multi-streams framework model (MSF),⁴² which examines the nuanced

35 See for example David Dolowitz and David Marsh, ‘Who Learns from Whom: A Review of the Policy Transfer Literature’ (1996) 44 *Political Studies* 343; David Benson and Andrew Jordan, ‘What Have We Learned from Policy Transfer Research? Dolowitz and Marsh Revisited’ (2011) 9 *Polit Stud Rev* 366.

36 See for example Daniel Béland and Robert Henry Cox, *Ideas and Politics in Social Science Research* (New York, NY: OUP, 2011); Marij Swinkels, ‘How Ideas Matter in Public Policy: A Review of Concepts, Mechanisms, and Methods’ (2020) 2 *International Review of Public Policy* 281.

37 See for example Paul A. Sabatier, ‘An Advocacy Coalition Framework of Policy Change and the Role of Policy-Oriented Learning Therein’ (1988) 21 *Policy Sci* 129; Kingdon, n 13 above; Darren Halpin and Grant Jordan, *The Scale of Interest Organization in Democratic Politics: Data and Research Methods* (Dordrecht: Springer, 2012).

38 See for example Paul Pierson, *Politics in Time: History, Institutions, and Social Analysis* (Princeton, NJ: Princeton University Press, 2004); B. Guy Peters, *Institutional Theory in Political Science: The New Institutionalism* (Cheltenham: Edward Elgar, 4th ed, 2019).

39 Michael Keating, Paul Cairney and Eve Hepburn, ‘Policy Convergence, Transfer and Learning in the UK Under Devolution’ (2012) 22 *Regional & Federal Studies* 289.

40 *ibid*; Greer, n 8 above.

41 Katherine E. Smith and others, ‘Divergence or Convergence? Health Inequalities and Policy in a Devolved Britain’ (2009) 29 *Crit Soc Policy* 216.

42 Kingdon, n 13 above.

dynamics of policymaking by taking account of problems, organised interests, and political considerations. The MSF has been widely used in the policy studies and comparative politics literatures; it provides a useful tool for analysing policy dynamics across jurisdictions (beyond its inception in the federal US system) and their reliance on multiple phenomena aligning.⁴³ The MSF focuses on three process streams within a system of policy formation. The *problem stream* considers how issues come to be defined as problems, and how these come to be recognised as requiring government action to resolve them.⁴⁴ The *policy stream* consists of numerous policy proposals. Within this ‘primeval policy soup’, proposals are identified and assessed to develop feasible options for action.⁴⁵ The *political stream* consists of political factors such as national mood, administrative or legislative turnover, and campaigns by pressure groups, and recognises that policy agendas which align with these factors may be more likely to rise to prominence.⁴⁶

Kingdon suggests the streams are largely independent of one another until a ‘policy window’ opens and they converge. This will happen when a ‘problem is recognized, a solution is developed and available in the policy community, a political change makes it the right time for policy change, and potential constraints are not severe.’⁴⁷ Most frequently, windows open where a compelling problem arises, either through events which occur in the political stream, or the efforts of policy entrepreneurs. This group is defined as ‘people who are willing to invest their resources in pushing their pet proposals or problems, are responsible not only for prompting important people to pay attention, but also for coupling solutions to problems and for coupling both problems and solutions to politics.’⁴⁸ ‘Coupling’ refers to how a particular policy solution is married to a problem and identified as the appropriate course of action.

Despite its wide use, some commentators argue that we ought to question in what circumstances the MSF should be used, especially given it may not easily translate into the UK context, having been developed in a federal system.⁴⁹ Whilst we consider that Kingdon’s model is useful for identifying and explaining policy processes, we recognise a richer understanding may be gained by reconciling and connecting his approach with other frameworks or theories.⁵⁰ For example, Cairney combines Kingdon’s model with the role of ‘ideas’ to analyse the development of smoking bans in a devolved UK, arguing that

43 Scott L. Greer, ‘John W Kingdon, Agendas, Alternatives, and Public Policies’ in Steven J. Balla, Martin Lodge and Edward Page (eds), *The Oxford Handbook of Classics in Public Policy and Administration* (Oxford: OUP, 2016).

44 Kingdon, n 13 above, 5.

45 *ibid.*, 6.

46 *ibid.*, 7.

47 *ibid.*, 165.

48 *ibid.*, 20.

49 Daniel Béland and Michael Howlett, ‘The Role and Impact of the Multiple-Streams Approach in Comparative Policy Analysis’ (2016) 18 *Journal of Comparative Policy Analysis: Research and Practice* 221.

50 Michael Howlett, Allan McConnell and Anthony Perl, ‘Weaving the Fabric of Public Policies: Comparing and Integrating Contemporary Frameworks for the Study of Policy Processes’ (2016) 18 *Journal of Comparative Policy Analysis: Research and Practice* 273.

combining these two frameworks provides a means to highlight the ‘idiosyncratic reasons for apparently similar policy developments.’⁵¹

We suggest that Kingdon’s model can be augmented (and can retain its utility for the UK context) by recognising the role of the connection–friction axis. We suggest that our conceptual approach allows for a richer consideration of the ways in which policymaking is impacted by the interconnected nature of the UK nations. The superimposition of a UK-wide health system and nation-specific political and constitutional contexts means that when individual nations develop or reform health law and policy, a consideration of the broader UK context and the position of other devolved nations is required. What may follow from this are episodes of friction between the UK and devolved governments, as well as between other policy and political actors, as they seek to navigate the opening and closing of policy windows in this process. These frictions can be reduced, if not eliminated, through pursuing political, institutional, or value-based connections, with actors cultivating allies, developing joint strategies, and sharing resources.⁵²

CASE STUDY: OPT-OUT ORGAN DONATION REFORM

Having outlined our conceptual-analytical framework, we now turn to the organ donation law reform process, using this as case study to explore the connection–friction axis in devolved health policy and law-making in the UK. As noted above, all the UK nations have now moved to an opt-out system for organ donation. However, rather than looking in detail at the contents of the legislation, we focus on the dynamics of policy-making processes which facilitated law reform in this area. We use Kingdon’s MSF model to highlight instances of connection–friction and examine the role they played in structuring processes. Before looking at each of the MSF’s streams, we provide a brief overview of the UK’s organ donation system and the law reform that took place.

The UK’s system for organ donation and legislative reform

The system to facilitate organ donation for transplantation is managed on a UK-wide basis by NHS Blood and Transplant (NHSBT). A specialist NHS Authority, NHSBT’s Organ Donation and Transplantation Directorate supports the donation pathway, managing the national organ donor register and co-ordinating the donation process via 12 Regional Organ Donation Teams (based across the UK nations).⁵³ NHSBT also manages the National Organ Retrieval Service and organ allocation processes, offering matched organs to individuals on the waiting list. The matching process operates on a UK-wide

51 Paul Cairney, ‘The Role of Ideas in Policy Transfer: The Case of UK Smoking Bans since Devolution’ (2009) 16 *J Eur Public Policy* 471.

52 Sabatier, n 37 above; Harrington, Hughes-Moore and Thomas, n 10 above.

53 NHS Blood and Transplant, ‘Who We Are’ at <https://www.nhsbt.nhs.uk/who-we-are/> [<https://perma.cc/9M6X-EBL6>].

basis; therefore, an organ donated in Northern Ireland may well be allocated to a recipient in Wales, and vice versa.⁵⁴ To some extent therefore, questions surrounding the organ donation system will necessarily be considered on the UK-wide level, despite legislative processes taking place discretely in each nation, in line with its devolution settlement.

Two main pieces of legislation govern organ donation for transplantation in the UK: the Human Tissue Act 2004 (HTA 2004) which covers England, Wales, and Northern Ireland,⁵⁵ and the Human Tissue (Scotland) Act 2006 (HTA 2006) which only applies in Scotland.⁵⁶ These statutes were adopted following *inter alia* a wave of major law reform in the early 2000s in the wake of high-profile organ retention scandals.⁵⁷ This reform embedded a so-called 'opt-in' model for organ donation, where 'appropriate consent' (per the HTA 2004) or 'authorisation' (per the HTA 2006)⁵⁸ needed to be obtained from individuals to donate their organs after death.⁵⁹ Designated family members could also provide consent or authorisation to donate their deceased family members' organs.⁶⁰

The opt-in model remained the legislative position for several years; the primary focus to increase deceased organ donation rates became institutional reform.⁶¹ Notwithstanding significant success in this regard, the issue of family veto remained an enduring obstacle to increase donation rates.⁶² Over time, this led to calls for reforming the legal frameworks to institute an opt-out regime for deceased organ donation,⁶³ we explore the reasons behind these calls further below.

The first nation to move to the opt-out model was Wales; the Welsh Assembly passed the Human Transplantation (Wales) Act 2013 (HTWA 2013) in July 2013. This legislation established a 'deemed consent' regime which came

54 NHS Blood and Transplant, 'National Organ Retrieval Services' at <https://www.odt.nhs.uk/retrieval/national-organ-retrieval-services/> [<https://perma.cc/N2C6-P3LJ>].

55 HTA 2004. Note this no longer applies to deceased organ donation which is covered by the HTWA 2013.

56 HTA 2006.

57 For an overview see for example J. Kenyon Mason and Graeme T. Laurie, 'Consent or Property? Dealing with the Body and Its Parts in the Shadow of Bristol and Alder Hey' (2001) 64 MLR 710; Margaret Brazier, 'Retained Organs, Ethics and Humanity' (2002) 22 Leg Stud 551.

58 For an overview of why the term 'authorisation' was preferred in the Scottish context, see Independent Review Group, 'Retention of Organs at Post-Mortem: Final Report' (Edinburgh: Scottish Executive Health Dept, 2001).

59 For an overview, see Farrell and Dove, n 4 above, 433.

60 HTA 2004, Pt 1, s 2; Pt 2, s 27(4) and (5); HTA 2006, Pt 4, s 50.

61 Organ Donation Taskforce, 'Independent Report: The potential impact of an opt out system for organ donation in the UK' (2008) at <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/4250/thepotentialimpactofanoptoutsystemfororganandonationintheuk.pdf> [<https://perma.cc/4DDW-X4J9>].

62 For further details regarding the persisting difficulties with family veto in the case of deceased organ donation in the UK prior to the most recent law reform, see David Shaw and Bernice Elgar, 'Persuading Bereaved Families to Permit Organ Donation' (2014) 40 Intens Care Med 96.

63 See for example British Medical Association, 'Opt-out for organ donation – changing hearts and minds' at https://www.bma.org.uk/media/7776/the-bmas-campaign-on-organ-donation-across-the-uk.pdf?_gl=1*6a80vx*_up*MQ..*_ga*MTY2MTUwODQ2Mi4xNzA0ODgxMzIx*_ga_F8G3Q36DDR*MTcwNDg4MTMyMC4xLjAuMTcwNDg4MTMyMC4wLjAuMA [<https://perma.cc/AG6T-KM3Z>].

into force on 1 December 2015. As regards England, the UK parliament passed deemed consent legislation in 2019; the Organ Donation (Deemed Consent) Act 2019 made amendments to the HTA 2004 which entered into force in March 2020. Scotland's 'deemed authorisation' legislation, the Human Tissue (Authorisation) (Scotland) Act 2019 (ASA 2019), was also passed in 2019 and amended the Scottish HTA 2006. The ASA 2019 came into force on March 2021 to allow time to conduct awareness-raising campaigns about the change of law in Scotland.⁶⁴ Northern Ireland was the last UK nation adopt an opt-out regime; the Organ and Tissue Donation (Deemed Consent) Act (Northern Ireland) 2022 (DCANI 2022) was passed in February 2022. This amended the HTA 2004 as it relates to Northern Ireland and entered into force in June 2023. As we discuss further below, the delay in adopting this law reform in Northern Ireland is largely attributable to ongoing contestation over power-sharing arrangements between the DUP and Sinn Féin. This had led to successive collapses of such arrangements, which were most recently restored in February 2024 after a two-year absence.⁶⁵ In the end, supplementary legislation was passed by the UK parliament to facilitate the implementation of the DCANI 2022.⁶⁶

Whilst a detailed analysis of these pieces of legislation is outside the scope of this article,⁶⁷ the regimes created have clear similarities. On a practical level, each means that if an adult has not registered their intention or objection to donate their organs on the national organ donation register, it will be presumed that they consent to/authorise the use of their organs after death.⁶⁸ The presumption of consent/authorisation can be rebutted by a family member or close friend, where there is reasonable evidence that the deceased person would not wish to donate their organs.⁶⁹ There is a list of exclusions from the opt-out system, which includes organs which would be considered novel in transplantation.⁷⁰ Additionally, for children, non-resident adults, or adults who lack capacity, express consent/authorisation is still required.⁷¹ With the exception of England, duties have been placed on ministers in the devolved nations to promote and resource the organ donation system.⁷² It is perhaps unsurprising that the leg-

64 See discussion in Jordan A. Parsons and Greg Moorlock, 'A Global Pandemic Is Not a Good Time to Introduce "Opt-out" for Organ Donation' (2020) 20 *Med L Int'l* 1; Jordan A. Parsons, 'Deemed Consent for Organ Donation: A Comparison of the English and Scottish Approaches' (2021) 8 *JLB Isab*003.

65 'NI's government has returned Stormont – what you need to know' *BBC News* 3 February 2024 at <https://www.bbc.co.uk/news/uk-northern-ireland-67726389> [<https://perma.cc/D9LG-Q23V>].

66 Northern Ireland (Executive Formation and Organ and Tissue Donation) Act 2023.

67 For which see James F Douglas and Antonia J. Cronin, 'The Human Transplantation (Wales) Act 2013: An Act of Encouragement, Not Enforcement' (2015) 78 *MLR* 324; Parsons, n 64 above; Jordan A. Parsons and Bonnie Venter, 'Deemed Consent for Organ Donation in Northern Ireland' (2022) 12 *The Lancet Regional Health – Europe* 100254.

68 HTWA 2013, s 4; HTA 2004, ss 3(6)-(6B); HTA 2006, s 6.

69 HTWA 2013, s 4(4); HTA 2004, s 3(6B).

70 With some minor differences in definition as to excluded organs. For a discussion on this point, see Nicola J. Williams, Laura O'Donovan and Stephen Wilkinson, 'Presumed Dissent? Opt-out Organ Donation and the Exclusion of Organs and Tissues' (2022) 30 *Med L Rev* 268.

71 HTWA 2013, ss 5-6; HTA 2004, ss 3(9)-(9A); HTA 2006, ss 6E, 6F, 8.

72 HTWA 2013, s 2; HTA 2006, s 1; Health (Miscellaneous Provisions) Act (Northern Ireland) 2016, s 15. Any promotional requirements in England are delegated to NHSBT.

islative parameters are broadly the same; taken together, the statutes needed to create some form of workable system for facilitating deceased organ donation across the UK through NHSBT.⁷³ However, to move beyond this, we need to focus on the dynamics of the process of opt-out organ donation law reform in a devolved UK, the instances of connection and friction across the problem, policy, and political streams, and how this influenced how and when the shift to opt-out took place.

The problem of organ donation

According to the MSF model, the problem stream contains problems which are considered 'public', in that they require some form of government response to solve them.⁷⁴ Problems can come to the attention of policymakers through indicators, which can occur for example from regular monitoring, such as population disease rates, or via specific focused events.⁷⁵ In the context of organ donation for transplantation in the UK, our participants demonstrated a shared understanding of the problem which opt-out donation sought to address: a lack of available organs for transplantation (ie organ shortage) as compared to the demand for these organs. We suggest this is reflective of the connected nature of the organ donation system in the UK and the institutions that deliver it. With a single system dealing with retrieval and allocation across the UK, increasing the availability of organs is not a problem that concerns only one nation, but remains, to some extent at least, a collective endeavour.

A closer look at the constituent elements also demonstrated a degree of consistency. First, participants across all nations spoke of a need to increase the availability of organs in the face of a narrow donor pool. In England, there was a recognition of the need to maximise the potential 'pool of donors' to increase the probability of donation.⁷⁶ This was mirrored in Scotland; one participant for example spoke of the need to widen the 'funnel' of eligible donors.⁷⁷ Second, a connection was made between the availability of organs for transplantation and the problem of family veto. Prior to the reforms enacted in relation to UK human tissue legislation, family refusals for individuals who had opted in to organ donation were stated in Scotland to be between 30 per cent and 50 per cent,⁷⁸ and in Wales, family veto was identified as contributing to the UK's low consent rates.⁷⁹ In speaking about the UK system as a whole, it was suggested that even where the system is able to identify possible organs for donation, the family's refusal of consent prevented these organs ultimately being transplanted.⁸⁰ As a result, it was argued that individuals' wishes to donate their

73 As stated by Participant 1. Whilst this does not mean duplication is necessary, it does denote the need for some level of consistency.

74 Béland and Howlett, n 49 above.

75 Kingdon, n 13 above.

76 Participant 17.

77 Participant 7.

78 SB 18-73 (2018).

79 Senedd Cymru 13/002 (2013).

80 Participant 1.

organs were not being respected and that an opt-out system would be better positioned to ensure this.⁸¹ Finally, it was recognised that there was a need to shift cultural attitudes to create an expectation around organ donation.⁸² Participants often made reference to Spain as an example of a country where organ donation was the norm and which enjoyed very high consent rates.⁸³

This suggests that, whilst representations of the policy problem were multifaceted,⁸⁴ the elements mentioned, as well as the language used in policy documents and by participants, remained largely consistent. This appears to reflect the connected nature of the UK-wide organ procurement and allocation system and a sense of shared endeavour in this regard. However, when indicators were used to call attention to the problem within policy discourse, what emerged was a high degree of local specificity at individual nation level. For example, in debates in the Northern Ireland Assembly and Holyrood, speeches which referenced the number of individuals who died whilst waiting for an organ focused specifically on patients in Northern Ireland or Scotland.⁸⁵ This approach localised a shared connection (in this case, the UK-wide organ shortage) to bring the problem to the attention of policymakers. As such, the problem was positioned along the connection-friction axis as requiring a collective (ie UK-wide) endeavour in terms of the ultimate policy objective, but the strategy adopted speaks to a recognition of the need for differentiated and localised approaches to realise this objective at the devolved level.

Potential policies

Within the policy stream, the MSF model identifies that policy solutions are developed from myriad possibilities, circulating within the ‘policy primeval soup’ where they are proposed and refined by various actors over time.⁸⁶ These suggestions are narrowed down to feasible options for policy action, with input from relevant actors and within the constraints of extant constitutional powers.⁸⁷ Here, experts play an important role, bringing not only relevant experience but also recognised expertise in the policy area. They offer analysis of

81 Participant 6.

82 Participant 20 (England and Wales), Participant 10 (Northern Ireland) and Participant 1 (pan-UK).

83 *ibid.* Whilst Spain also uses an opt-out system, its high donation rates are frequently attributed to its strong infrastructure and donation pathways. See Rafael Matesanz and others, ‘How Spain Reached 40 Deceased Organ Donors per Million Population’ (2017) 17 *Am J Transplant* 1447; Simon Streit and others, ‘Ten Lessons from the Spanish Model of Organ Donation and Transplantation’ (2023) 36 *Transplant Int* 11009.

84 Carol Lee Bacchi, *Analysing Policy: What’s the Problem Represented to Be?* (Frenchs Forest, NSW: Pearson, 2009).

85 Scottish Parliament, Stage 1 Debate Transcript (26 February 2019) at <https://www.parliament.scot/bills-and-laws/bills/human-tissue-authorisation-scotland-bill> [<https://perma.cc/9L5D-5BSJ>]; NI Assembly, Stage 2 Debate Official Report (Monday 20 September 2021) at <https://aims.niassembly.gov.uk/officialreport/report.aspx?eveDate=2021/09/20&docID=349761#3608976> [<https://perma.cc/W8CW-BP6V>].

86 Kingdon, n 13 above.

87 Béland and Howlett, n 49 above.

problems, propose policy solutions, and evaluate both the efficacy of potential solutions and the likelihood of successful implementation.⁸⁸ The advice of experts is often weighted heavily by political leaders in search of solutions to policy problems; for example, in the context of health, medical professionals are key experts and have considerable influence over the direction of UK policy.⁸⁹ As will be demonstrated below, our empirical research findings showed that expert discourse contributed to longstanding political friction within nations surrounding the feasibility of opt-out reform. In response, connections between stakeholders emerged to keep this reform option on the political agenda.

Opt-out organ donation has long been part of the policy ‘soup’ and was the subject of various Members’ Bills in Westminster in the early 2000s.⁹⁰ However, there was considerable resistance at this time to its adoption as an appropriate policy solution to the organ shortage problem. The most notable expert group in early debates was the Organ Donation Taskforce (ODT), established by the UK government in partnership with the devolved governments to consider what policy actions were required to increase organ donation rates. Comprising health professionals, NHS managers, ethicists and patient advocates, the Taskforce published two reports in 2008 which were highly influential in the policy stream.⁹¹ The second report, focusing on opt-out donation specifically, considered it was not a suitable policy solution. Among other things, the ODT noted that any new legislation would require significant resourcing, could undermine the concept of organ donation as a ‘gift’, and could also contribute to the erosion of trust in the organ donation system.⁹² It also raised doubt as to whether adopting opt-out would result in an increased number of donated organs.⁹³ Instead, the ODT considered the appropriate policy solution was a comprehensive institutional overhaul of organ donation and retrieval within the existing legislative framework.⁹⁴ This led to the development of the current organ donation system and involvement of NHSBT (who could be characterised as another expert actor). Ongoing dissent from experts continued to create friction within the policy stream. For example, opposition to opt-out legislation (or at a minimum mixed opinion) within the medical community was noted by various participants,⁹⁵ and this contributed to the failure of a Member’s Bill brought forward by Jo-Anne Dobson (then-elected Member of the Legislative

88 *ibid.*

89 Rudolf Klein, ‘The State and the Profession: The Politics of the Double Bed’ (1990) 301 *BMJ* 700.

90 See for example The Transplant of Human Organs Bill [HC], put forward in the 2000–01 parliamentary session by Rt Hon Kenneth Clarke QC MP; Kidney Transplant Bill [HL], put forward in the 2007–08 Parliamentary Session by Baroness Finlay of Llandaff.

91 Department of Health, ‘Organs for Transplants: A Report from the Organ Donation Taskforce’ (16 January 2008) at https://web.archive.org/web/20081205103228/dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082122 (last visited 11 January 2024); ‘The potential impact of an opt out system for organ donation in the UK’ n 61 above.

92 ‘The potential impact of an opt out system for organ donation in the UK’ *ibid.*, 34.

93 *ibid.*

94 *ibid.*

95 Participants 3, 7, 8, and 9

Assembly (MLA)) in 2015, which sought to introduce the approach in Northern Ireland.⁹⁶

In spite of this expert opposition, policy entrepreneurs continued to advocate for opt-out and worked together to position it as a viable policy solution.⁹⁷ Stakeholder connections formed both within and between nations in order to garner political support and manage or overcome any ongoing friction. This included the ‘Transplant Partnership’ – a stakeholder coalition organised by the British Medical Association (BMA) in the early 2000s, which developed into a lobby group that continued to push for opt-out law reform, including through meetings with civil servants.⁹⁸ The British Heart Foundation (BHF) was another key policy entrepreneur, with involvement across all four nations. Participants spoke of the BHF’s work in Wales in partnership with Kidney Wales,⁹⁹ BHF Scotland supported a Member’s Bill brought forward by Anne McTaggart, an elected Member of the Scottish Parliament (MSP) in 2015,¹⁰⁰ and gave evidence to the Scottish Parliamentary Committee which subsequently scrutinised the ASA 2019.¹⁰¹ Additionally, in Northern Ireland, the BHF formed a partnership with Donate4Dáithí, a campaign group for opt-out led by the parents of Dáithí Mac Gabhann, a (now) six-year-old boy on the heart transplant waiting list.¹⁰² This showed the success of policy entrepreneurs, with connections across the UK, working together with policy communities and political actors to share campaign strategies for opt-out reform, while also capitalising on local campaigning opportunities. This indicates that, much like the problem stream, a mixture of both UK-wide and nation-specific strategising took place to push opt-out as a policy solution.

Aside from the makeup of these stakeholder groups, how they collectively agreed and conceptualised opt-out appeared to be important to gaining acceptability within the policy stream. Policy entrepreneurs portrayed opt-out not as an alternative to other policy solutions, but as *complementary* to them. This consisted of recognising that legislative change via opt-out was not a ‘silver bullet’, but was instead part of a wider endeavour to change UK culture to make organ donation the norm.¹⁰³ This characterisation of opt-out aligned with one of the ODT’s earlier recommendations about making organ donation

96 David Maxwell, ‘Organ Donation: Transplant Surgeons Warn over Donor Law Change’ *BBC News* 16 November 2015 at <https://www.bbc.co.uk/news/uk-northern-ireland-34837989> [<https://perma.cc/Z9UW-SFDR>].

97 Kingdon, n 13 above.

98 Participants 7, 9, and 21. See also British Medical Association ‘Building on Progress: Where Next for Organ Donation Policy in the UK?’ (February 2012) 3 at <https://www.bma.org.uk/media/3729/bma-organ-donation-building-on-progress-feb-2012.pdf> [<https://perma.cc/BN57-M8YF>].

99 Participant 4.

100 Hannah Rodger, ‘MSP and Charity Join Forces to Spread Opt Out Message’ *Glasgow Times* 10 July 2014 at <https://www.glasgowtimes.co.uk/news/13285030.msp-and-charity-join-forces-to-spread-opt-out-message> [<https://perma.cc/2KPE-UJAD>].

101 SP 467 (2019).

102 Christopher Leebody, ‘Donate4Daithi Dad Nominated for Heart Hero Award by British Heart Foundation’ *Belfast Telegraph* 20 November 2022 at <https://www.belfasttelegraph.co.uk/news/northern-ireland/donate4daithi-dad-nominated-for-heart-hero-award-by-british-heart-foundation/42158708.html> [<https://perma.cc/H9CW-3NNY>].

103 Participant 9.

‘usual, not unusual’.¹⁰⁴ By taking this position, policy entrepreneurs depicted opt-out as supporting an increase in organ donation rates *and* a change in culture, as well as being consistent with the earlier ODT recommendations and consequent changes to the organ donation system in the UK.

Similarly, some opponents of opt-out put forward the argument that a preferable method to increase organ donation rates would be to educate, raise awareness, and to provide greater financial support to the organ donation system.¹⁰⁵ However, policy entrepreneurs addressed such points by integrating the goal of public awareness within their opt-out reform proposals. Across all nations, participants agreed that adoption of opt-out went hand-in-hand with publicity campaigns and ongoing awareness.¹⁰⁶ This featured strongly in political debates and policy papers. For example, Joe Fitzpatrick MSP (the Minister responsible for bringing the Scottish Bill forward) stated in his Stage 1 speech in the Scottish Parliament: ‘Good public awareness will be crucial to achieving the aim of increasing support for donation. The Bill builds on the provisions in the [Human Tissue (Scotland)] 2006 Act for Ministers to support and raise awareness of donation by introducing a requirement to raise awareness of the new authorisation processes that it introduces.’¹⁰⁷

The crucial issue of raising awareness about the importance of organ donation allowed policy entrepreneurs to also establish points of agreement with those opposed to opt-out reform. This was highlighted by one participant who detailed an exchange they had with a clinician opposing opt-out: ‘[They were saying] that the way to go through it is awareness and education, and so I was able to say I totally agree 100 per cent that education and awareness is the way forward.’¹⁰⁸ This demonstrates that friction was navigated by policy entrepreneurs through making connections based on shared aims and positioning opt-out as being able to respond to various points raised by those who opposed such reform.

Finally, the prior acceptance of other policy solutions (including those recommended by the ODT) enabled policy entrepreneurs to portray opt-out as a logical next step towards increasing organ donation rates: that is to say, that a turn to law was both sensible and necessary, particularly to address ongoing problems with family veto. As one participant noted:

if I take you back to 2008, there was the [ODT] report and that led to a dramatic change in organ donor rates. But that dramatic change was because we changed the infrastructure, we improved the organ donation infrastructure and the care pathways for organ donation, so that we knew what was happening at every stage of the care pathway and we were identifying opportunities that may have missed or opportunities for improvement at every stage ... So our pool of potential donors dramatically increased. But what has stayed fairly stubbornly the same is our consent rate.¹⁰⁹

104 Department of Health, n 91 above.

105 Participant 8.

106 See for example Participants 3, 4, 10, and 15.

107 Scottish Parliament, Stage 1 Debate Transcript, n 85 above.

108 Participant 10.

109 Participant 1.

Consequently, arguments could be made by policy entrepreneurs that now that the organ donation infrastructure had been improved in accordance with the earlier ODT recommendations, the ‘timing was right’ to reconsider a move to opt-out reform.¹¹⁰ Indeed, law was positioned as an enabler of further progress, supported by views from the senior clinicians (again highlighting the role of medical experts in this area) that the infrastructure was in place and the UK (or the particular nation within it) was ‘ready’ for opt-out.¹¹¹

Devolution politics

The political stream focuses on political factors, for example public opinion, political changes within executive and legislative bodies, or influential campaigns by advocacy groups.¹¹² Here, our empirical research suggested that friction plays a significant role within the political stream, shaping activities in relation to opt-out reform in and across the UK’s four nations. In Northern Ireland, for example, political friction created by a combination of the legacy of the Troubles, dysfunctional power-sharing arrangements, and the dynamics of local party politics proved highly influential. We have noted above that the earlier 2015 Dobson Bill was not supported in the Northern Ireland Assembly, in part due to the opposition of influential local transplant clinicians. This demonstrates the influence that medical experts can wield over legislative actors and how their support for – or opposition to – a particular course of action could influence perceptions of a policy in the political stream.

However, participants also suggested that another significant reason for the earlier Bill’s failure may have been down to party politics within the Northern Ireland Assembly; friction arose from longstanding political divides between local parties. For example, the UUP, a Unionist party, was not able to gain support for opt-out law reform at the time from Sinn Féin, a Nationalist party. One participant also suggested that the DUP opposed the reform simply because it had been proposed by the UUP: ‘it was basically politics, the [DUP] were saying, well, we didn’t bring it forward so we’re just going to mess about with it for a while and block it.’¹¹³ Subsequent to the failure of the Dobson Bill, power-sharing arrangements in Northern Ireland collapsed in January 2017. This resulted in the absence of a functioning Executive or Assembly for a further three years and meant no new policy could be taken forward by the devolved administration.

This ongoing instability and persistent political friction between local parties meant that there was no possibility of advancing opt-out reform in the immediate term. Although campaign groups such as Donate4Dáithí lobbied political actors and worked to persuade local councils in Northern Ireland to pass motions in support of a change in the law, the lack of a functioning

110 Participant 3.

111 Participants 3, 9, 10, and 21.

112 Béland and Howlett, n 49 above.

113 Participant 11.

legislature proved to be a barrier to further progress.¹¹⁴ Even after the reinstatement of power-sharing institutions in January 2020, one participant observed that political friction continued to present challenges:

In the midst of all of this we had the pandemic, we had politicians breaking lockdown rules, causing political instability, we had Brexit negotiations ... So from week to week you really didn't know was the Assembly going to fall again and, therefore, legislation is not able to be passed? ... So, we found ourselves in May/June 2021 realising that if this legislation process ... didn't start asap there was not going to be enough time left in the mandate to get it completed.¹¹⁵

Various participants also highlighted that for any legislation to progress to (and through) the Northern Ireland Assembly, it required the approval of both the First Minister (DUP) and Deputy First Minister (Sinn Féin). However, political turmoil within the DUP itself meant that this did not happen.¹¹⁶

Within Scotland, political friction was also evident, with an initial legislative opt-out reform attempt (the 2015 McTaggart Bill) failing to progress due to opposition from the SNP. This was against the background of what was recognised by one participant as a 'volatile' time in Scottish politics, namely impending Scottish parliamentary elections and the Brexit referendum in 2016:

I also think there was a lot of party politics involved, that it was a Labour MSP that was passing it and I don't think the Scottish Government were particularly comfortable with the idea of such a major piece of health legislation passing three months before the election. And I think there was unfortunately a comment by an SNP MSP who said, if Jackie Baillie [a Labour MSP] hadn't spoken in the first stage debate, it would have passed. But because Jackie Baillie was one of the sponsors, the SNP voted against it.¹¹⁷

In Wales, political friction at a constitutional level also impacted plans to introduce opt-out reform. The Welsh Government first consulted on the policy in 2008, and although it was not supported by the Welsh Assembly's Health, Wellbeing, and Local Government Committee, the Welsh Government continued to keep the policy on the table by suggesting that public opinion was clearly in favour of opt-out reform, with support from the BHF and Kidney Wales.¹¹⁸ The major barrier, however, was the requirement to seek a LCO from the UK government (per the devolution settlement at the time, discussed above). The Welsh Government initiated the LCO process on 10 January 2011,¹¹⁹ however successive UK governments indicated little political appetite to support an extension of powers.¹²⁰ As such, there remained governmental uncertainty as to whether the Welsh Assembly had legislative

114 Participant 10.

115 Participant 9.

116 Participants 9, 10, and 11.

117 Participant 7.

118 Participant 4.

119 See The National Assembly for Wales (Legislative Competence) (Health and Health Service) Order 2011.

120 Participants 4 and 14.

competence in this area and whether it might face a constitutional challenge from the UK government as a result.¹²¹ The option of seeking an LCO was therefore dropped in March 2011.

Further political challenges arose for the Welsh Government in the legislative drafting process during 2012–13. For example, the Stage 1 debate on the general principles which would underpin the legislation was especially tumultuous, leading to 42 suggested amendments. This had to be overcome by political actors who supported the deemed consent Bill in the Welsh Assembly, through a process of negotiation and concessions (discussed in more detail below).

As for England, political friction between the UK and Welsh Governments also adversely impacted upon the former's support for opt-out reform. This became more acute once the Welsh Assembly passed the HWTA 2013, with participants suggesting the UK government was reluctant to be seen to support or emulate the Welsh Government's agenda, as well as its use of devolved health competence more generally. One participant described the broader Welsh approach to health, including stewardship of the NHS, as a 'political football' in the UK parliament; it was used by Conservative Party politicians to point to political mismanagement on the part of the Welsh (Labour) Government.¹²² Against this backdrop, when Geoffrey Robinson MP brought forward a Private Member's Bill in support of opt-out in 2017, he faced significant political hurdles. This was not only due to the political friction between the UK and Welsh Governments just discussed, but also the lack of published data demonstrating the effectiveness of the HTWA 2013 in Wales.¹²³ In political terms, the lack of data raised further questions about whether the Welsh legislative example was useful with regards to increasing organ donation rates.¹²⁴ Interestingly, the UK government position was in contrast to the views expressed by a number of participants from Scotland and Northern Ireland. They instead considered the territorial proximity of Wales, including similarities with their respective health systems (in contrast to international examples such as Spain), to be beneficial in terms of shared experiences and learning. Both in substance and in terms of assurance that legislative change could be brought off, the Welsh example helped, rather than hindered, the move towards opt-out in those nations.¹²⁵

In the face of such challenges, the activities of policy entrepreneurs and their joint campaigns in and across the UK's four nations needed to exert pressure to gain political support. One way this took place was through presenting real-life emotive stories of individuals and their families waiting for available organs. This placed public pressure on political actors and operated to gain them as allies, suggesting that political frictions could be dissolved by connecting the problem of organ donation to these individual cases.¹²⁶ This was evident in Northern Ireland through the Donate4Dáithí Campaign which lobbied politicians to support opt-out law reform and maintained public attention on

121 Participant 13.

122 Participant 25.

123 See Jordan A. Parsons, 'Welsh 2013 deemed consent legislation falls short of expectations' (2018) 122 *Health Policy* 941.

124 Participant 14.

125 Participants 6 and 9.

126 See John Harrington, *Towards a Rhetoric of Medical Law* (Abingdon: Routledge, 2017) ch 3.

it.¹²⁷ In England, the BMA stakeholder coalition (mentioned previously) and political actors also worked with the editors of the Daily Mirror newspaper to develop their media campaign. Pressure for opt-out reform was connected to the development of the ‘Law for Life campaign’, which began in 2015. This developed into a campaign for ‘Max and Keira’s Law’; the story of Max Johnson receiving a heart from Keira Bell was used by the Daily Mirror to create public pressure for a change in the law.¹²⁸

A final facet of the political stream where connections can be drawn is the desire to galvanise public opinion in support of opt-out reform, as well as the virtues of organ donation more generally. Here, we once again identified the issue of representation,¹²⁹ as well the use of shared strategies. Advocates for opt-out were able to point to a mismatch between overwhelming public support for organ donation and those who signed up to become donors. These statistics could then be used by political actors to champion law reform on a UK-wide level, as well as within each nation. This was ultimately reflected in the Explanatory Notes of the various opt-out Bills submitted to the UK Parliament and devolved legislatures. As one of our participants argued: ‘the policy background to this provision is to amend the law on when consent is considered to have been given to better reflect the views of the 80 per cent of the population that support organ donation in principle.’¹³⁰ The idea of bringing the law into line with public opinion was positioned as a central concern of the opt-out legislation in England in parliamentary debates.¹³¹

Opening policy windows

When it came to coupling the streams to opening the policy window, stakeholders and policymakers worked to make connections and overcome political friction both between and within nations. We provide select examples below – in doing we do not seek to suggest that they were the *only* incidences of friction, or the *only* reason that the legislation was successfully adopted. Rather, we seek to highlight the ways in which such friction operated and was either exploited or overcome to facilitate opt-out reform.

As previously noted, pre-existing political friction between the Welsh and UK governments over the use of LCOs in the context of Welsh devolution arrangements made opt-out legislation challenging to pursue in Wales.¹³² However, the 2011 Welsh referendum on law-making powers and the re-election of the Labour Government in Cardiff combined to provide an opportunity to move forward with legislation. Because there was now no need to seek an

127 Participants 9, 10, and 11.

128 Participants 4 and 17. For further background context, see NHS Blood and Transplant, ‘Organ Donation Law Change Awareness Campaign Launches’ (NHSBT, 25 April 2019) at <https://www.organdonation.nhs.uk/get-involved/news/organ-donation-law-change-awareness-campaign-launches/> [https://perma.cc/YJ87-LRVK].

129 Bacchi, n 84 above.

130 Participant 3.

131 HC Deb vol 636 col 446 23 February 2018, Geoffrey Robinson MP.

132 HC 896-I (2011), 29 March 2011; Wales Office Cm 7992 (2011).

LCO, further political friction with the UK government could be avoided, as one participant observed:

what really changed things was the referendum in 2011 on the ability then of the Assembly, as it was then, to create primary legislation. Without that, we would have had to go through the never-ending process of LCOs and LCMs and obtaining permission from Westminster and then drafting a Measure. All that, fortunately, went flying out the window with the referendum in 2011. So, it cleared the way for us then to introduce the legislation in a way that, well, certainly wouldn't have been possible before 2007 and certainly would have been more difficult pre-2011.¹³³

Participants also viewed opt-out legislation as signalling to the UK government that Wales was now competent to pursue significant and innovative legislation on its own. As a result, the previous political friction created around the exercise of Welsh powers now provided an impetus for opt-out legislation, rather than acting as an obstacle to its successful adoption. There was a recognition at a political level in Wales that opt-out reform could be brought forward as an early piece of legislation in the Welsh Assembly to demonstrate the benefits of increased legislative competence and Cardiff's ability to act as an independent legislature. As one participant pointed out: 'because there'd been this previous discussion and informal consultation, it was probably viewed as something that had perhaps been developed a little bit more fully and that it was able to perhaps be brought forward a little bit more quickly.'¹³⁴

Prior to the introduction of the deemed consent Bill in the Welsh Assembly in December 2012, longstanding connections between the Welsh governments, experts, and policy entrepreneurs helped build support, with a series of briefings taking place with the relevant Assembly Committees. Research was initiated by Lesley Griffiths (then-member of the Assembly (AM)) to address concerns previously raised by the Assembly's Health Wellbeing, and Local Government Committee.¹³⁵ She worked in tandem with Kidney Wales and the BMA on various campaigns to ensure that opt-out reform was kept in the public and political consciousness. As one participant observed: 'there had been an expectation built up that this would happen among civic society, we talked about it for so long, we'd campaigned, we had thousands of families of people who were receiving care and wanting a donation, needing a donation, waiting for one and so on, we had them all on side campaigning and talking to their AMs, as they then were.'¹³⁶

Therefore, the change in the devolution settlement in Wales, as well as connections between political actors and policy entrepreneurs, allowed the policy window to open. It was also made possible because of the continuity of the Labour governments in Wales, which created the opportunity for deeper and

133 Participant 13.

134 Participant 4.

135 Fiona McAllister and Adam Blunt, 'Research to support Wales' organ donation opt-out proposal consultation' (Welsh Government, 14/2012); Mellisa Palmer, 'Opt-out systems of organ donation: International evidence review' (Welsh Government, 44/2012); Melissa Palmer, 'The role of families in organ donation: International evidence review' (Welsh Government, 45/2012).

136 Participant 14.

long-lasting relationships to be built between political actors, experts, and policy entrepreneurs. For example, various participants noted that despite the failure of the LCO, Edwina Hart AM, the BMA, and Kidney Wales nevertheless maintained informal communication in relation to campaigns run to gain public and political support for opt-out reform, as well as continuing to respond to relevant government consultations. The adoption of opt-out legislation as a Labour manifesto pledge, as well as the commitment of a series of Labour Health Ministers, including Lesley Griffiths AM and Mark Drakeford AM (subsequently First Minister of Wales), strengthened the case for opt-out reform.¹³⁷ This type of support carried through to the passing of the HTWA 2013.

Participants specifically pointed to the importance of Mark Drakeford's role in maintaining dialogue between various political actors during development of the Bill. This was in addition to continuing briefings with civil servants and meetings with opposition politicians behind-the-scenes, which helped manage the numerous amendments that had been proposed during the Bill's passage through the Assembly.¹³⁸ As political friction between the UK and Welsh governments was now not an issue, the resilient longstanding local connections between political leaders, policymakers, and policy entrepreneurs proved key in successful adoption of the legislation.

In relation to England, the opportunity to pass opt-out legislation in the UK Parliament arose partly out of luck, with a slot for legislative reform being obtained through a Private Member's Bill. Nevertheless, a range of participants pointed out that this was capitalised on by Dan Jarvis MP who persuaded Geoffrey Robinson MP (the ballot winner) to bring forward an opt-out Bill in that slot and supported it in the House of Commons.¹³⁹ They suggested that Mr Jarvis also facilitated connections across various groups; he worked with the Daily Mirror newspaper on their media campaign, with the BMA, NHSBT, and other external stakeholders, and helped secure support for the motion from senior figures in the Conservative Government, including Jeremy Hunt MP and then-Prime Minister Theresa May MP.¹⁴⁰

Participants indicated that the cross-party group of supporters were then able to plan strategically (with the media, charities, and campaign groups) to overcome any reticence about being seen to emulate Wales, as well as seeking to avoid potential political friction between the nations. For example, headlines relating to the Daily Mirror's campaign for Max and Kiera's Law were planned to coincide with key political events, including party conferences and legislative stages, and this kept the pressure on political actors to ensure successful passage of opt-out legislation.¹⁴¹ Evidence of public support could be characterised by political supporters as something that was desired by a majority in

137 Participants 15, 21, and 23.

138 *ibid.*

139 Participants 2, 17, 21, and 22.

140 Participant 25; 'Theresa May's shift towards presumed-consent organ donation praised by charities and patients' *Independent* 5 October 2017 at <https://www.independent.co.uk/news/uk/politics/theresa-may-organ-donation-policy-praised-transplants-presumed-consent-opt-out-system-conservative-conference-a7984021.html> 2 [https://perma.cc/V2TQ-BL2U].

141 Participant 22.

the country;¹⁴² reform could be viewed as a positive news story in the context of the challenging Brexit negotiations which were ongoing at the time. In the end, this resulted in Conservative Party leaders having informal conversations with their parliamentary colleagues to encourage support for the Bill, and it ultimately passed with minimal opposition.¹⁴³ As one participant observed:

Once you have Prime Minister, once you got Secretary of State, you're in a pretty good place. But we weren't complacent about it, and we wanted to ensure that there was widespread backbench support, and we wanted the opposition support as well. So through the opposition's office, I was able to make representations to him via a key member of his staff who had a personal interest in the issue, and she went away and undertook to secure the support of the leader of the opposition and successfully did so. So by then we had all of the key players lined up.¹⁴⁴

Support from the UK government in drafting the deemed consent Bill, as well as cross-party support, also assisted in minimising subsequent amendments, making the Bill much more likely to pass, rather than lapse, in the parliamentary session in which it had first been introduced.¹⁴⁵

More broadly, there appears to have been a growing awareness in UK governmental circles that not engaging in opt-out reform and seeking to maintain the status quo was likely to become increasingly politically problematic. One participant suggested Wales' decision to move ahead with an opt-out regime added 'potency to the argument' for law reform in England, in that it created a lack of legal consistency and raised questions as to why England was failing to follow suit.¹⁴⁶ As another summarised:

I think that it had happened in Wales was helpful. I think despite the complications [the tensions between the UK and Welsh governments], it was useful context, that essentially within the UK, you now had a postcode lottery. So if you were living in Wales, things will be different. And obviously 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 and or Swindon or Monmouth, or whatever, it might be so that it was happening in a part of the United Kingdom. And at that stage, I think I'm right in saying they've already been positive noises about Scotland as Scotland weren't there yet, but I think they were on the journey as well.¹⁴⁷

This is suggestive of a potential political concern that failing to reform existing organ donation laws – in a manner that was compatible with both a shared jurisdiction for organ donation (Wales) and shared infrastructure (with Scotland) – could lead to accusations of a 'postcode lottery' and potential high-profile or constitutionally important legal challenges down-the-track.¹⁴⁸ Thus, the need

142 Participant 17.

143 Participant 25.

144 Participant 25.

145 Participant 2.

146 Participant 17.

147 Participant 25.

148 Participants 25 and 17.

to ensure a joined-up UK approach appears to have influenced both the UK government and back-benchers to lend their support to the legislation.

In Scotland, as noted above, the 2015 McTaggart Bill had proposed opt-out, but proved unsuccessful in part due to existing political friction both within Scotland and beyond. Nevertheless, the Bill's failure appears to have catalysed the Scottish Government to take on opt-out reform. While the Scottish Parliament's Health and Sport Committee scrutinised the McTaggart Bill and did not support it, the Committee recommended that the Scottish Government take forward a consultation on how best to increase organ donation rates, which included considering whether opt-out was a suitable reform option.¹⁴⁹ In response to this, the Government agreed to prepare its own opt-out legislation in the next parliamentary session.¹⁵⁰ As noted by one participant, through the McTaggart Bill, 'the Government realised that there was a case for change and that [they] should, as Government, look to take that forward.'¹⁵¹ The Scottish Government duly moved forward with the ASA 2019. In the circumstances, it could be suggested that the friction between political parties in Scotland was ultimately productive. As one participant recognised, Government-led legislation was desirable, in that it would be both easier to get through Parliament, and more comprehensive as a result of 'the raft of Government lawyers behind it'.¹⁵²

The development of the Scottish Government's Bill also pointed to well-established connections between Scottish lawmakers, experts (such as the medical community), and policy entrepreneurs. This meant, similarly to Wales, that once the Government had committed to opt-out, its development was well-supported at local level and it could move forward with relative ease. For example, the Scottish Donation and Transplant Group, an expert group of patients and professionals who were experienced in organ donation,¹⁵³ were involved with policy development from the outset and were heavily consulted throughout the process and helped contribute to the shape and content of the legislation. Participants noted that provisions regarding pre-death procedures, unique to the Scottish legislation, were presented to the group to ensure they would work in practice.¹⁵⁴ A member of staff was also seconded from NHSBT; they held sessions with MSPs, which participants suggested helped gain supporters by providing clarity on how opt-out legislation would work in practice.¹⁵⁵

Support was also drawn from policy entrepreneurs; groups such as the BHF regularly conducted public opinion polling and could assist proponents of the Bill with 'intelligence about what the noise was like on the ground',¹⁵⁶ helping

149 SP Paper 894 (2016).

150 Maureen Watt MSP, Letter to Duncan McNeil MSP, Convener Health and Sport Committee, 'Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill' (8 February 2016) at http://archive2021.parliament.scot/S4_HealthandSportCommittee/Inquiries/20160208-SG_Response_Transplantation_Bill.pdf (last visited 11 January 2024).

151 Participant 6.

152 Participant 7.

153 Scottish Government, 'Scottish Donation and Transplant Group' at <http://www.gov.scot/groups/scottish-donation-and-transplant-group/> [<https://perma.cc/YAB8-9HZQ>].

154 Participant 3.

155 Participant 6.

156 Participant 7.

maintain a picture of consistent public support. Accordingly, whilst the political friction experienced may have been within Scotland, rather than with another UK nation, it nevertheless appeared to have galvanised political action to pursue opt-out reform. Like Wales, this occurred in circumstances where support was drawn from well-established local connections between the various actors.

Turning to Northern Ireland, we have already noted the longstanding political friction in local party politics, with entrenched sectarian divides in the context of an inherently unstable constitutional settlement. In these circumstances, the Donate4Dáithí campaign was key in navigating such friction and did so by connecting with other policy entrepreneurs, as well as with individuals on all sides of the political spectrum. As one participant noted: ‘[Dáithí] went right across all political parties, he had them all eating out of his hand. Which, for Northern Ireland is quite a trick! So ... Donate4Dáithí and then British Heart Foundation and Kidney Care were really, really good ... I think the big part about it was they kept it in the public eye, they didn’t let the pace drop ... especially Dáithí, he got in everywhere. He was in sports teams, you know, he was everywhere right through the whole sort of process.’¹⁵⁷

Other participants spoke of the personal commitment shown by Mr Robin Swann, the Northern Ireland Minister for Health, in championing the deemed consent Bill in the Assembly, as well as publicly working with the Donate4Dáithí campaign to ensure that it remained on the legislative agenda.¹⁵⁸

A final point which speaks to connections was the view amongst various policy actors that Northern Ireland was ‘out of step’ with the other UK nations. As stated by one participant: ‘we were falling behind the rest of the UK at that stage and [the Act] was bringing us up. Basically, the problem was that the other jurisdictions were going a certain way, had the guidance and everything that was being followed and we were sitting behind that.’¹⁵⁹ This aligns with similar concerns expressed by other participants regarding the English position about the need to create a coherent organ donation system on a UK-wide basis, and the importance of aligning with legislative developments across the rest of the UK.

In Northern Ireland, there were also occasions where a policy window which had apparently opened to facilitate opt-out reform suddenly threatened to close due to political friction, thus requiring a swift response on the part of local policy entrepreneurs. We highlight two examples. In June 2021, the Bill was awaiting executive approval (a necessary step prior to proceed to the Northern Ireland Assembly). If this approval did not come before the summer recess, there would be insufficient time for the Bill to pass through to the adoption stage.¹⁶⁰ The lack of agreement from the First Minister at the time, Paul Givan (DUP), led the Donate4Dáithí Campaign to tweet a graphic which stated ‘DUP: WHY ARE YOU BLOCKING SOFT OPT-OUT DONATION?’¹⁶¹ Following

157 Participant 11.

158 Participants 9, 10, and 11.

159 Participant 11.

160 Participants 9 and 10.

161 Donate4Dáithí Campaign tweet, (24 June 2021) at <https://twitter.com/Donate4Daithi/status/1407996388370272256> [<https://perma.cc/MQB5-Z626>]. For details on differing opt-out approaches see n 3 above.

significant engagement with the tweet on social media, Mr Givan contacted the campaign directly and by the end of the day he had given the required approval.¹⁶² As such, the Bill reached the Assembly and progressed quickly with no amendments made.¹⁶³ This was in part a testament to the level of cross-party support, but was also due to the fact that the Bill was straightforward and largely mirrored the English version, which had already been implemented. Indeed, participant 11 suggested this was a deliberate choice, given the English system was operational and functional, as well as the fact that the provisions for Northern Ireland were also contained within the same legislation (the HTA 2004).

A further instance occurred after the opt-out legislation had been passed by the Northern Ireland Assembly but before its implementation. With the DUP refusing to form an Executive and there being no functioning Assembly, crucial secondary legislation which was required to bring the legislation into force could not be passed. As a result, it threatened to become a casualty of local political friction, with DUP opponents arguing that they should form an Executive to allow the Assembly to operate, and the DUP suggesting in response that the UK government should step in and pass the relevant legislation in the UK parliament.¹⁶⁴ Once again, the Donat4Dáithí campaign acted to ensure that opt-out legislation would come into force. They met with UK parliamentary representatives and successfully lobbied to ensure the secondary legislation was passed.¹⁶⁵ Despite significant political friction within Northern Ireland, the connections between Northern Ireland and the rest of the UK, as well as between the policy entrepreneurs and political actors who supported opt-out legislation, allowed such political friction to be overcome in order to ensure that it came into force.

ANALYSING THE CONNECTION-FRICTION AXIS

How best to address organ shortage could be considered a niche policy problem for the UK's four nations. Indeed, it affects a very small number of individuals and does not represent a significant expenditure of NHS time and

162 Participant 10.

163 Northern Ireland Assembly, 'Official Report: Tuesday 08 February 2022' at <https://aims.niassembly.gov.uk/officialreport/report.aspx?&eveDate=2022/02/08&docID=366587#3947384> [<https://perma.cc/G9B9-AXUV>].

164 David Young, 'DUP under mounting pressure to drop Assembly veto to let organ donor law pass' *Independent* 10 February 2023 at <https://www.independent.co.uk/news/uk/chris-heatonharris-dup-northern-ireland-stormont-speaker-b2279759.html> [<https://perma.cc/627V-HRRT>].

165 Jayne McCormack, 'Dáithí's Law on organ donation clears final hurdle in Commons' *BBC News* 22 February 2023 at <https://www.bbc.co.uk/news/uk-northern-ireland-64723591> [<https://perma.cc/9EAF-MTBE>]. This was not unique to Dáithí's Law and Westminster intervention was similarly required for the implementation of legislation decriminalising abortion in Northern Ireland. See Alexandra Topping, 'UK government preparing to override Northern Ireland on abortion services' *The Guardian* 24 March 2022 at <https://www.theguardian.com/uk-news/2022/mar/24/uk-government-to-override-northern-ireland-on-abortion-services> [<https://perma.cc/QA3F-A3D9>].

resources.¹⁶⁶ Yet, across the course of 10 years, legislation came to be seen as a necessary and appropriate step to manage the supply and demand problem, and to navigate arising friction. Drawing on Kingdon’s MSF model, our analysis suggests that the ‘opening’ of respective policy windows, and the operation of the connection–friction axis, was intimately tied to the nature of the UK’s differentiated devolution settlements. Each has evolved differently over time, yet the potential for political connectedness on a UK-wide basis within the health policy sector has remained. When it came to the dynamics of policymaking processes for organ donation law reform, there were notable differences in approaches taken by policy communities, policy entrepreneurs, medical experts, and political actors, as well as drivers for political alignment, or conversely political friction.

In Northern Ireland, for example, much of the impetus for opt-out reform came from policy entrepreneurs who actively sought connections with political actors and medical experts in order to open the policy window, and to combat long-standing and entrenched political and constitutional friction. In Wales, opt-out reform proceeded as a result of the connectedness of the policy community and political government, with collectively agreed values.¹⁶⁷ Reform was catalysed by change to the Welsh devolution settlement itself; this provided for expanded legislative powers which circumvented the threshold of political and constitutional conflict, via Westminster. Obtaining such powers provided an opportunity not only to change the organ donation system, but (as noted above) to signal the benefits of devolution in the area of health more generally. This was coupled with a stable Labour government and established local policy connections, enabling a more ambitious approach to health policymaking, as part of the Welsh government driving a Welsh-specific and innovative political agenda. Work done *behind the scenes* ensured that opt-out reform remained high on this agenda, in addition to facilitating the successful passage of opt-out legislation through the newly empowered Welsh Assembly.

In Scotland, relatively stable political arrangements, which resulted from the SNP being long established in power, meant that the Scottish Government was able to set its own agenda and could draw on established contacts with medical experts and policy entrepreneurs to shape opt-out legislation as it passed through the Scottish Parliament. As noted above, the close connections between actors in Scotland and Wales and their territorial proximity meant that Scotland could draw on, and learn from, the earlier experience in Wales with regards to opt-out reform. Similarly, UK-wide institutional connections also meant that the insights offered by NHSBT proved to be helpful in terms of the development of Welsh opt-out reform, as well as shaping how the opt-out system would work in practice in Scotland.

Concerning England, connections were utilised in various ways. Because, like Scotland, England was not the first nation to adopt opt-out, policy en-

166 For an overview, see NHS Blood and Transplant, ‘Organ Donation and Transplantation 2030: Meeting the Need’ (ODT Clinical, Key strategies, 2020) at <https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/meeting-the-need-2030/> [<https://perma.cc/X8LW-G4EQ>].

167 Harrington, Hughes Moore and Thomas, n 10 above.

trepreneurs could draw on examples, data, research, and planning from the devolved nations to demonstrate and maximise workability of opt-out reform (for example in relation to media campaigns). Indeed, Wales was characterised very much as a policy ‘experiment ground’ by participants.¹⁶⁸ Whilst explicit political comparison had the potential to foment friction in policy and law reform processes, the lessons learned from policy experimentation in Wales and the opt-out infrastructures created could be utilised by UK-wide organisations, such as NHSBT and the BMA, to devise strategies for creating public awareness and, if necessary, political pressure to facilitate reform. Additionally, lines of intra-governmental communication operated between civil servants in and across the UK nations provided opportunities to share policy learning and to avoid potential pitfalls which might give rise to political friction. This was particularly noticeable, for example, in the attempts made to align opt-out legislation in England, and subsequently in Northern Ireland.

As noted above, the UK government was aware of the challenges of being out of step with the devolved nations and this in part appears to have provided the political catalyst for action in England and eventually Northern Ireland. This was captured in concerns on the part of political leaders at being ‘left behind’ in both nations. Ultimately, this proved to have a significant impact in terms of information-sharing across the UK nations regarding policy options, as well as practical insights on how best to proceed with opt-out reform to ensure legislative success. Beyond questions of politics, our empirical research findings revealed that the unique nature of devolution arrangements created opportunities for interconnectedness between the UK’s four nations, but that success in health policy and law reform might ultimately turn on the extent to which such connectedness contributes to successful management of political friction in and across the nations. This may be particularly acute in policy areas which – like organ donation for transplantation – raise contested political or ethically sensitive concerns.¹⁶⁹ What such findings also show is that law – specifically opt-out legislation in the chosen case study – proved to be a medium for both friction and connection. Not only was law reform a site where friction arose and around which it was structured, but it also provided impetus for the achievement of connections between local and national policy communities to manage such friction.

Drawing on our analysis of empirical research findings, we would suggest that taking account of the connection–friction axis – around which devolved health policy and law-making takes place – is likely to prove useful in the context of increasingly distinct political environments and diverse policy coalitions that have been formed and now operate in each of the UK’s nations. Whilst the UK’s devolution arrangements may be unique, the connection–friction axis has the potential to be applied more widely in terms of understanding policy-creation,

168 Participants 6 and 9.

169 See n 6 above. As a further example in the health context, law is also increasingly used to manage political and ethical contestation around abortion provision, see for example Sally Sheldon and others, *The Abortion Act 1967: A Biography of UK Law* (Cambridge: CUP, 2022); Emily Ottley, ‘Fixed Buffer Zone Legislation: A Proportionate Response to Demonstrations Outside Abortion Clinics in England and Wales?’ (2022) 20 *Med L Rev* 509.

policy-sharing and law-making in other devolved or federal systems, including where constitutional arrangements afford shared or delegated powers in relation to health services, policy and law-making.

CONCLUSION

In this article, we examined the dynamics of devolved health policy and law-making in the UK, drawing on a case study of organ donation. Given that health is a significant area of devolved competence, such case studies offer the opportunity to examine both similarities and differences in approach between the four nations in the context of the UK's evolving constitutional settlement.¹⁷⁰ We argued that there was a need to move away from the traditional characterisation of the devolved health policy-making process which is grounded in a convergence–divergence approach, towards one that recognises the connection–friction axis around which this process takes place. Findings from empirical research conducted as part of the case study showed that while connectedness between government stakeholders, experts, and advocacy groups was clearly vital in structuring the policy process, account should also be taken of how law operates as a medium for achieving connection and managing friction, particularly where local and UK-wide management is required for successful implementation. Moreover, the case study suggests that law is being used as a preferred mechanism for managing politically sensitive issues in areas of devolved policy competence. This was certainly the case in relation to the shift to opt-out organ donation and such factors are likely to be relevant to a range of health policy issues. Going forward, it would be important to explore how the connection–friction approach proposed in this article could be applied to analyse the dynamics of policy, including policy transfer, and law-making, across a range of health and other policy issues in the context of differentiated devolution settlements in the UK and beyond.

170 See further John Harrington and Abbie-Rose Hampton, 'Border Country: Health Law in Devolved UK' (2024) 32 *Med L Rev*, DOI: 10.1093.