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## Introduction

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### Abstract

We all need to access health care at some point in our lives – and some may have a more continual or dramatic engagement with that care than others. As such, health law and ethics is a subject which is, and should be, of everyday importance and significance to everyone. In this collection, we have brought together emerging and established scholars in the broad field of health law and ethics to explore, assess and evaluate the development of scholarship in the field by considering selected ‘leading works’ and their impact on the subject as a whole. This chapter explains why health law and ethics ‘matters’, what is meant by ‘leading work’, and how the leading works and the contributors were selected. The structure of each chapter is also set out, and a brief outline of the leading work considered in each chapter, along with key arguments, is provided.

### Introduction

In an article surveying the field of health law and ethics, Margot Brazier and colleagues noted, that:

‘[t]omorrow looks busy for medical lawyers and ethicists. But ‘yesterday’ is important too. Yesterday’s questions and debates evolve into today’s concerns and tomorrow’s avenues of enquiry, necessitating fresh appraisal of transmuting dilemmas.<sup>1</sup>

We agree that it is important to look back on the scholarship in the field of health law and ethics for at least two reasons: to remind ourselves of that scholarship, which can sometimes get ‘lost’ in the plethora of literature that now comprises our field, and because important lessons can be learnt and drawn from reviewing such literature.

With this in mind, in this collection we have brought together emerging and established scholars in the broad field of health law and ethics in order, most obviously, to contribute to the *Leading Works* series, which seeks:

(i) to map current understandings of legal sub-disciplines by identifying leading works in them; (ii) to show how these works give identity to the legal sub-disciplines, shaping them and plotting their development; and (iii) to provide a vehicle for critique of the way the works constitute the legal sub-disciplines.<sup>2</sup>

Our contributors thus explore, assess and evaluate the development of scholarship on health law and ethics, and consider its potential future development by focusing upon their selected ‘leading works’ in the subject.

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<sup>1</sup> Margaret Brazier and others, ‘Editorial: Reflections on Bioethics and Law: Yesterday, Today and Tomorrow’ (2018) 26 *Med Law Rev* 179, 182. doi.org/10.1093/medlaw/fwy019.

<sup>2</sup> Russell Sandberg, ‘Series introduction’ in Russell Sandberg (ed), *Leading Works in Religion* (Routledge 2019) xi-xv, xiii.

### ***Why consider health law and ethics?***

We all need to access health care at some point in our lives – and some may have a more continual or dramatic engagement with that care than others. Health law and ethics is thus a subject which is, and should be, of everyday importance and significance to everyone.

Over the last 50 years, health law and ethics has established itself as an important area of academic study in the UK and beyond. It is one of the most popular optional modules for UK undergraduate law students, and most law schools offer at least one module on it. The number of textbooks on health law and ethics has increased during this time, as well as the number of specialist journals, edited collections, and monographs. The individual topics/issues which fall under its umbrella have thus been the subject of rigorous research. A growing body of literature which has charted the history of health law and ethics as a subject in the UK,<sup>3</sup> as well as reflected on key topics and issues within the subject by, for example, providing feminist perspectives on them,<sup>4</sup> writing ethical judgments on key cases,<sup>5</sup> or identifying and analysing landmark cases.<sup>6</sup> At the same time, topics within the area have been the subject of judicial attention nationally, including in the Supreme Court, and in the European Court of Human Rights, as well as in courts across the globe.

Yet, health law and ethics has always been a subject of (and to) change – in terms of nomenclature,<sup>7</sup> content, validity and parameters.<sup>8</sup> Changes may be the result of scientific advances, legal and/or ethical understandings, global developments and/or emergencies, and, more recently, based on empirical research. Thus, the scope of health law as a subject has changed over the years, as well as the theoretical perspectives used by scholars within it.

In the light of the above, we believe that it is important to question, analyse, and understand the development of health law and ethics as an academic subject, and to explore its likely future development through the lens of leading works.

### ***What makes a leading work?***

The Collins dictionary defines ‘leading’ as ‘guiding, directing or influencing’,<sup>9</sup> and Russell Sandberg (in his Introduction to the *Leading Works* series) suggests that a leading work is one that has helped to shape and plot development in the relevant field.<sup>10</sup> Helpfully for us,

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<sup>3</sup> Margaret Brazier and Jonathan Montgomery, ‘Whence and whither “modern medical law”?’ (2019) 70 *NILQ* 5. doi.org/10.53386/nllq.v70i1.229

<sup>4</sup> Sally Sheldon and Michael Thomson (eds), *Feminists Perspectives on Health Care Law* (Cavendish 1998), as discussed in the chapter by Sara Fovargue in this collection.

<sup>5</sup> Stephen Smith and others (eds), *Ethical Judgments: Rewriting Medical Law* (Hart 2017).

<sup>6</sup> Jonathan Herring and Jesse Wall, *Landmark Cases in Medical Law* (Hart 2015); Shaun Pattinson, *Revisiting Landmark Cases in Medical Law* (Routledge 2020).

<sup>7</sup> Some, such as Jonathan Montgomery, believe that ‘medical law’, in too narrowly focusing on the doctor-patient relationship, overlooks the role of non-medical health care professionals: Jonathan Montgomery, *Health Care Law* (Oxford University Press 2002) 2. This view has, in turn, been criticised for being too narrow and overlooking the fact that health care is often provided *outside* of the health care system and professional-patient relationships: Tamara Hervey and Jean McHale, ‘Law, health and the European Union’ (2006) 25 *LS* 228, 232. doi.org/10.1111/j.1748-121X.2005.tb00614.x.

<sup>8</sup> As discussed in the chapter by Sara Fovargue in this collection.

<sup>9</sup> Collins Online Dictionary <<https://www.collinsdictionary.com/dictionary/english/leading>> accessed 21 October 2022. Many thanks to Judy Laing for providing us with this definition.

<sup>10</sup> Sandberg (n 1) xiii.

one of our contributors (Bonnie Venter) has suggested that a leading work has five attributes and that it:

- provides an original contribution or makes a new claim and so changes (or at least has the potential to change) the way we usually think about an issue or a topic.
- paves the way for future research while not necessarily providing all the answers.
- has some sort of impact in or on legal or clinical practice, which could include providing a more in-depth understanding of an issue or topic.
- should at least, and to some extent, have continuing relevance.
- should, ideally, not exist in a vacuum and so should include social and political considerations where relevant.<sup>11</sup>

Without directly setting out or addressing these matters, the leading works selected by our contributors do, in our opinion, meet these criteria.

However, we have not been prescriptive when defining the concept. As such, our contributors have interpreted the meaning of ‘leading work’ in different ways. Some have chosen works that they think have been leading within the field of health law and ethics more broadly or within their area of expertise more specifically, some have chosen works that have influenced their own research, and others have selected works that they think *should* be regarded as leading although they may not yet be seen as such.

### ***Selecting contributors and the leading works***

In order to identify contributors, we issued a call for papers, as well as inviting contributions from some scholars. We actively sought to involve scholars at different career stages, and we shared our call for papers via the Society of Legal Scholars Health Law email list, as well as the Northern Bioethics list. Although our primary focus is on English law, we are delighted to have attracted scholars from across the globe.

With regard to the works selected, Russell Sandberg, in his introduction to the *Leading Works* series, said that the selection approach to his collection on law and religion was ‘akin to Radio Four’s *Desert Island Discs* or BBC One’s *Room 101*’, where each contributor was given free rein in their choice.<sup>12</sup> In this collection, we considered asking contributors to select a work that fell within one of the topics listed in the contents of most health law and ethics textbooks, but decided that we did not want to adopt such a prescriptive approach and that it would also be hard to select one work on each topic to be covered. Instead, we adopted Sandberg’s approach. and we invited our contributors to suggest up to three leading works that they would like to consider and once we had an overview of the preferred works and the topics they would address, we sought to include leading works that would cover a range of issues and topics within the fields of health law and ethics.

Having said that, as the leading works were self-selected, we are not attempting here to provide or replicate a health law and ethics canon. Thus, as Sandberg has said:

the leading works chosen are not meant to be exhaustive; they are simply illustrative and a means by which the contributors reflect upon the often unspoken question about

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<sup>11</sup> See the chapter by Bonnie Venter in this collection.

<sup>12</sup> Sandberg (n 1) xiv.

how and why a sub-discipline has developed in the way that it has and its likely and desired future development.<sup>13</sup>

This means that several topics routinely considered in health law and ethics modules are not included in this collection. No authors chose, for example, to consider works looking at medical treatment of young children or mature minors, withdrawing treatment, or professional regulation.

If we were asked, as individual editors, to develop a list of leading works in the field, we might have come up with very different lists. And, as editors, we likely would not be able to agree on a single list among ourselves as to what constituted the health law and ethics canon, never mind one that might satisfy the readers of this collection. Many leading authors who have undoubtedly had a significant impact on health law and ethics are not included in this collection. This is not to say that they have not produced leading works, merely that our authors did not select them. We believe we could easily have filled ten volumes with works that would fit the bill for inclusion here. But that is, in a way, the point of the collection – to start conversations and reflections on what can/should be considered to be leading works in our field of concern.

### ***The structure of each chapter and of this collection***

The chapter order was something else we had to consider: did we order the chapters thematically, alphabetically by the author(s) of the leading work, or chronologically? We have chosen the latter in order to reflect, in a limited and partial way, how debates in health law and ethics have evolved. And as with other collections in this series, each chapter consists of four sections: ‘The Work’ in which the selected work is described and information about the author(s) of the work included by some contributors too; ‘The Context’, where the contributor explains the (academic/legal/political/social/) context in which the leading work was written and published; ‘The Significance’ - ‘the main part of each chapter: the analysis and discussion of the reason that the chosen work leads scholars in new directions’;<sup>14</sup> and ‘The Legacy’ in which the contributor summarises why the selected work is (or will be in the future) a leading work. Some contributors have also chosen to include brief ‘Introduction’ and/or ‘Conclusion’ sections too. The works selected span four decades, starting in 1970 and ending in 2017.

Starting chronologically in terms of date of publication, this collection opens with Anne-Maree Farrell’s chapter on Richard Titmuss’s *The Gift Relationship*, which was published in 1970. According to Farrell, Titmuss’s arguments about the importance of recognising altruistic impulses in blood donation have been highly influential as the gift relationship has become a core ethical principle underpinning human tissue policy and regulation at national and international levels. Fundamental ethical principles are also considered by Stephen Smith, in his discussion of *Principles of Biomedical Ethics* authored by Tom Beauchamp and James Childress. This text was first published in 1979, and the latest (6th edition) was published in 2019. Smith charts how Beauchamp and Childress’s, which focuses on the mid-level principles of autonomy, beneficence, non-maleficence and justice, has had an indirect but pervasive effect on health law and ethics. It is for this reason that *Principles of Biomedical Ethics* should be considered a leading work in health law and ethics.

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<sup>13</sup> Sandberg (n 1) xiv.

<sup>14</sup> Sandberg (n 1) xv.

We then move into the 1980s and Larry Gostin's 'The ideology of entitlement: The application of contemporary legal approaches to psychiatry', published in 1983, is the focus of Judy Laing's chapter. Laing argues that Gostin's pioneering work on mental health law helped inspire new thinking on the then young subdiscipline, and that his human rights influenced approach not only influenced law reform in the 1970s and 1980s but continues today. Just as Gostin is viewed as a pioneer in mental health law (as well as in public health law), Peter Skegg has been referred to as a 'master of medical law'.<sup>15</sup> In his chapter, Richard Huxtable considers Skegg's *Law, Ethics, and Medicine* (1984). Huxtable maintains that Skegg's scholarship has played a central role in the existence and respectability of health law and ethics as a field in its own right. He argues that Skegg's work demonstrated predictive powers, particularly in foreshadowing how the courts would decide cases on withholding or withdrawing life-sustaining treatment.

In her chapter, Emma Cave suggests that Mary Warnock's *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (1984) has stood the test of time as not only has it provided a durable legal framework for IVF and other reproductive techniques, but it also offered a pioneering regulatory model for new scientific developments. We finish the 1980s with José Miola's chapter in which he explains how he has been personally influenced as an academic by the 'What is a medical decision?' chapter from Ian Kennedy's 1988 collection, *Treat Me Right*. That chapter was initially delivered as a lecture in 1979 and then informed Kennedy's 1980 Reith Lectures, which were the basis of his 1983 influential *The Unmasking of Medicine*.<sup>16</sup> Miola argues that Kennedy's 'What is a medical decision?' chapter in *Treat Me Right* has not only been significant in terms of his own scholarship, but also for highlighting the problem of non-technical decisions made by doctors being wrongly categorised as 'medical' in nature.

David Rothman's *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* was published at the start of the 1990s (1991), and a key theme in it is the incursion of outsiders (lawyers and bioethicists) into the world of medicine. Mary Donnelly (an academic lawyer - 'outsider') and Barry Lyons (a clinician - 'insider') argue that Rothman's methodological and evaluative approach makes *Strangers at the Bedside* a leading work. In asking us to consider what bioethics and law have achieved, Donnelly and Lyons argue that Rothman requires us to critically reflect on the contemporary role of these disciplines and their ability to contribute to the rights, health and security of the public in the context of healthcare.

Different disciplinary perspectives are also brought together in a 1996 article by Margaret Brazier and John Harris - 'Public health and private lives'. Craig Purshouse argues that this is a leading work on the law and ethics of infectious diseases but that it has been overlooked despite Brazier and Harris' formidable arguments regarding the criminalisation of disease transmission, and also for its predictive powers in the light of the Covid-19 pandemic. Emily Jackson's choice, *Embodied Progress: A Cultural Account of Assisted Conception* by Sarah Franklin, also considers health care from a different perspective as is not a legal work but an ethnographic study of women undergoing IVF. Published in 1997, Franklin's *Embodied Progress* not only influenced Jackson's scholarship (which is discussed in Jo Bridgeman's chapter) but has also had wider significance in highlighting the unintended and unanticipated consequences of new technologies for patients. The decade concludes with a consideration of

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<sup>15</sup> Ron Paterson, 'Foreword' in Mark Heneghan and Jesse Wall (eds), *Law, Ethics and Medicine: Essays in Honour of Peter Skegg* (Thomson Reuters 2016) v-vii, vii.

<sup>16</sup> Ian Kennedy, *The Unmasking of Medicine* (Flamingo 1983).

Sally Sheldon and Michael Thomson's edited collection on *Feminist Perspectives on Health Care Law* (1998), considered by Sara Fovargue. In addition to the importance of the individual chapters, Fovargue argues that the collection as a whole is a leading work because of the different perspectives offered therein, along with alternative readings and interpretations of established doctrines.

The importance of feminist approaches is also a key feature of Jo Bridgeman's chapter on Emily Jackson's *Regulating Reproduction: Law, Technology and Autonomy* (2001). Bridgeman argues that Jackson's monograph is a leading work of critical health law scholarship for its emphasis on the importance of autonomy in its proposals for reform of the law regulating reproduction. Autonomy also plays a part in Roy Gilbar's discussion of Graeme Laurie's *Genetic Privacy: A Challenge to Medico-Legal Norms*, which was published in 2002. For Gilbar, Laurie's monograph is a leading work because it influenced scholarly debate on the application of privacy to genetic information. Legal developments, such as *ABC v St George's Healthcare NHS Trust* on the disclosure of genetic information,<sup>17</sup> together with technological advances such as biobanks, have, in Gilbar's view, only made Laurie's arguments more relevant because Laurie provides a comprehensive account of privacy and emphasises the interest of individuals to control genetic information when it becomes available. This, for Gilbar, is an important counter to dominant solidarity discourse. Laurie's willingness to modify his original account of genetic privacy in the light of relational concerns and perspectives is also viewed as a strength, and shows the adaptability of Laurie's arguments to new developments in the field.

In *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (2010), Jaime Lindsey argues that Mary Donnelly not only set the research agenda in mental capacity law (particularly in her call for empirical research in the field), which has since been taken up by other researchers (including Lindsey), but also provided a rigorous analysis of autonomy in health law generally. Autonomy is also a central concern in Janet Radcliffe Richards's provocative proposal for a market in kidneys, which is considered by Bonnie Venter. Venter argues that *The Ethics of Transplants: Why Careless Thought Costs Lives* (2012) is a leading work of continuing relevance for, amongst other things, making readers rethink the routes to organ donation, and that Radcliffe-Richards' moral reasoning might usefully be employed in relation to biotechnological developments in the field, such as xenotransplantation and 3-D bioprinted organs.

In the penultimate chapter, Louise Austin argues that Jonathan Ives's 2014 article 'A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics' should be considered a leading work because of his method of empirical bioethics known as reflexive balancing. This method, Austin suggests, can be used to find answers to research questions by integrating normative and empirical perspectives and is significant in its use of boundary principles to facilitate this integration. Such reflexive balancing can offer new understandings of much explored issues (for example, informed consent), and can also be applied to 'newer' matters of concern, such as moral distress in nursing or uterine transplants. Finally, Sarah Devaney argues that in the second edition of *Merry and McCall Smith's Errors, Medicine and the Law* (2017), and building upon the arguments in the first edition which was published in 2001, Alan Merry and Warren Brookbanks demonstrate that the traditional culpability approach to patient harm has failed to improve standards in healthcare. Their international and interdisciplinary approach is of particular note for her, and Devaney suggests that the

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<sup>17</sup> [2017] EWCA Civ 336.

contextualised conceptualisations of error, blame and accountability and the criticisms of blame as a central response to patient harm in *Errors, Medicine and the Law*, now lie at the heart of many modern patient safety policies. As such, the legacy of this leading work is both evident and enduring.

Our collection closes with a concluding chapter by Bernadette Richards, in which she skilfully identifies key themes across the collection and also reflects on her personal experiences within the field. Overall, our aim in this collection has been to respond to Sandberg's initial desire for the *Leading Works* series 'to fire a critical light at the way in which sub-disciplines regard themselves and perpetuate their identity'.<sup>18</sup> We hope that we have done justice to our subject.

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<sup>18</sup> Sandberg (n 1) xiii.