Reimagining Health Law

by Professor Jean McHale and Dr Atina Krajewska

Birmingham Law School

CEPLER Working Paper Series

Paper 04/2018

The Centre for Professional Legal Education and Research is a part of the Law School at the University of Birmingham.

For more information on CEPLER, visit: www.birmingham.ac.uk/cepler

For more information on the Working Paper Series, please contact: cepler@contacts.bham.ac.uk

cepler
PROFESSIONAL LEGAL EDUCATION AND RESEARCH
BIRMINGHAM LAW SCHOOL

CEPLER WORKING PAPER
Jean McHale and Atina Krajewska

REIMAGINING HEALTH LAW

On the 11th September 2018 a Reimagining Health Law Workshop took place at the Birmingham Law School. The Workshop aimed to explore the discipline of health law from a range of perspectives: doctrinal/historical/critical. Health law is a relatively young discipline, which has emerged from a backdrop of "Medical" and "Health Care" law and has developed rapidly in recent decades. The purpose of the meeting was to consider the disciplinary interface within and outside law, i.e. health law's connection to other legal fields, its relationship with bioethics, humanities, and social sciences, and their impact on the health law methodology. In particular the speakers addressed a number of pressing questions that have influenced the field in the past and will shape it in future.

The main questions that we set ourselves to answer were as follows: What do we mean when we write about, research on, or teach Health Law? Is there a unique health law method and if so, to what extent have the developments in other fields and disciplines contributed to the emergence of that method? To what extent is the fact that an academic scholar began as a public lawyer, which led to them working in health law, impacts on the way in which the discipline itself is framed? Are we witnessing any important paradigm shift in the field at the moment? We wanted to encourage the participants to reflect on different ideas and synergies framing health law and to question assumptions about what health law- was, is, and where it is going.

The Workshop was organised by Professor Jean McHale, the Director of the Centre for Health Law, Science, and Policy (CHLSP), and Dr Atina Krajewska, Senior Birmingham Fellow at the Birmingham Law School. It was jointly funded by CEPLER, the Birmingham Law School and CHLSP. Around 40 academic scholars, students, medics, and publishers' reps joined us for the day. Among them were the pioneers of medical law and bioethics who developed the discipline in the 1980s, prominent health lawyers of the day, and young researchers who will shape the field in the future.

The event was divided into four sessions:
SESSION ONE: HEALTH AND LAW- HOW DID WE GET HERE?
SESSION TWO: DIFFERENT LENSES OF HEALTH LAW
SESSION THREE: ACTORS, PRINCIPLES, METHODS
SESSION FOUR: "OUT WITH THE OLD AND IN WITH THE NEW": A LENS OF HOPE?

SESSION ONE: HEALTH AND LAW- HOW DID WE GET HERE?

In the first session, chaired by Professor Bob Lee, we took a closer look at the historic development of health law, the formation of medical law at the intersection of tort law, criminal law, and bioethics. We were fortunate to have with us (via video-link) Professor Margot Brazier from the University of Manchester, Professor Jonathan Montgomery from UCL, and (in person) Professor Phil Fennell from Cardiff University, all setting the trends in different areas of health law, both at the beginnings of its journey and today.

Margot Brazier (University of Manchester), in her talk entitled "Early Years of Health Law - An Accidental Journey?" talked about her experiences as a lecturer when medical law was at its infancy and the challenges that her and her colleagues, Sheila Maclean, David Price, Derek Morgan, and Ian Kennedy, faced when they attempted to establish medical law as a separate discipline. She started as follows:

"In universities across the United Kingdom in the last 15 years or so of the 20th century a 'new' area of academic research and teaching took flight – what most people then called medical law? In 1980 you would have struggled to find a course in medical law or more than the odd individual scholar researching the topic. In 2018, you would find courses in most LLB programmes, Masters Courses, PhD students and several research centres dedicated to what many now name health law. In many such centres health law contracted a marriage with what was once called medical ethics and now termed bioethics. How did this come about? What were the aims of this new breed of scholars? Who approved the developments? How did the scholars establish their competencies? Maybe they did none of these things and simply embarked on an accidental journey?"

In responding to these questions she highlighted the fact that the emergence of medical law coincided with the emergence of law and economics, environmental law, law and criminal justice and other sub disciplines. *"We need to ensure that we perceive the development of medical law in the context of its times and that our future may depend as much on the direction of travel of law school overall as your own effort."* She went on to discuss the evolution from medical law to health law and the limitations of every definition. While the intersections with other disciplines, including bioethics and medical history are crucial, health law has still a lot to offer in the fast changing world of medicine and science.

Jonathan Montgomery (University College London) continued to discuss the problem of labels and definitions raised by Margot in her talk. In his presentation entitled "What's in a name? The effects of labelling on our analysis of the role of law in health" he considered some of the labels that have been used by scholars

to define and theorise our subject area such as medicine law and ethics, medical law and ethics, public health care law, or global health law. He noted that "labels are the currency of power struggles, and we should excavate the aims and objectives that are served by their instrumental use in projects (descriptive and normative). They also act as cultural icons in socio-political-historical contexts. They point us to connections, social meanings and enable us to engage in shared conversations. They have important framing effects, making some things easier to see and obscure others, suggesting different questions for primary consideration, making some solutions more apparent than others. This can be seen in the contents of textbooks, the search for underlying unities, and the sense of purpose of scholars. He identified boundary cases for content; medicines, the right to die, capacity law as important for re-imagining the subject. Abortion was used to test underlying unities (ethics, rights to care, provider regulation, safety). In Jonathan's view interpretations of the House of Lords decision in *Gillick* and the Supreme Court decision in *Montgomery* show different senses of purpose among scholars.

Phil Fennell (Cardiff University) focused on the journey of mental health law and health and social care law in his talk entitled "Codifying Clinical Power: The Juridification of Health and Social Care". Recalling his experiences as a scholar and human rights advocate over the past 40 years. He reflected on the development of a key area of medical law during this period of academic development, namely the dramatic expansion and codification of various interwoven and overlapping regimes of statutory and common law powers to detain people with mental disabilities and treat them without consent. Phil considered these developments in the light of 21st Century human rights discourse. In relation to disability rights it has become customary to refer to old and new paradigm human rights. The old human rights paradigm acknowledges the legitimacy of tutelary relations, accepting the power of the state to detain and treat people with mental disabilities for paternalist reasons or for public protection, but insisting on restrictions on medical decision-making affecting the right to liberty, the right to be free from torture or inhuman or degrading treatment, and the right to physical and psychological integrity. The new paradigm seeks to prohibit all such interventions as manifestations of disability discrimination and social exclusion. The development of health and social care law over the past 40 years in terms of balancing expansion of clinical power against human rights protections for mentally disabled people and their families and carers were considered in the light of these two human rights paradigms. According to Phil Fennel it is the area of mental health and social care law where the most exciting innovations and battles are taking place. They should be very carefully analysed by health and human rights lawyers in the UK.

SESSION TWO: DIFFERENT LENSES OF HEALTH LAW

Katherine Wade from the University of Leicester chaired the second morning session, which focused on the different legal lenses through which health law can be viewed, analysed and developed.

Keith Syrett (University of Bristol) spoke about "Health Law through a Public Law lens". In his view the traditional focus of medical law upon the physician-patient relationship has tended to disguise both that healthcare is delivered within a systemic context, and that it performs collective functions. Public law provides a means of comprehending, analysing and evaluating the relevant organisational environment and societal goals and ought therefore to be considered as foundational to the teaching and research of health law. His talk sought to explicate this perspective, and its value for health lawyers, in more detail.

Jean McHale (University of Birmingham) on the other hand presented a detailed and critical analysis of "Health Law as a subset of Human Rights law. Really?" She started her presentation by recalling the third edition of their textbook Medical Law in 2000, in which Ian Kennedy and Andrew Grubb commented that medical law had one unifying theme – that of human rights. This well- known statement was itself preceded by Ian Kennedy's assertions that medical law could be seen as a subset of human rights law just over a decade earlier 1988 in his book Treat Me Right: Essays in Medical Law and Ethics. While on first glance there does seem to be a clear synergy between health law and human rights law this paper interrogates whether health law can really be said to be a subset of human rights law empirically and/or normatively. Jean began by examining what led Kennedy to make his original assertions and whether his original arguments were justifiable. She went on to analyse the legal developments in the UK over the last thirty years in the health law area including those since the Human Rights Act 2000 and doubted whether the original premises are met today. Her paper outlined a new intellectual project, which aims to unpack some of the different stories presented by engagement with human rights principles since October 2000 and the diverse responses they present.

SESSION THREE: ACTORS, PRINCIPLES, METHODS

The third session focused on the subjects and principles that constitute the discipline of health law. The session demonstrated the wealth of the theoretical accounts and conceptualisations of subjectivity in health law and how these shape the discipline. It paid particular attention to the recent landmark case of Montgomery (2015), which shifted the paradigm in the area of informed consent and redefined the way we view patient-doctor relationship.

It begun with the presentation by Marie Fox (University of Liverpool) "Embodying Health Law - who are the subjects of health law?". Her paper explored the contribution that new materialist and posthumanist approaches, which emphasise bodily processes and corporeal capacities, can make to re-imaging the contours of the legal subject. It takes up questions about the nature of matter and bodies, and the place of embodied humans within the ambit of health law. New ways of life and living can serve to complicate conventional ethical concepts such as personhood; while a shift in focus from 'the body' to embodiment as the object of analysis directs attention to forms of matter and embodied choices which are valued and validated by law. By dislocating agency as the property of a discrete self-knowing subject - whether the agency of patients or doctors (the traditional subjects of 'medical' law) - such approaches, in turn, allow health lawyers to resist representations of the legal subject as universal and disembodied. Additionally, as Marie pointed out, they call into question the various dichotomies and oppositions (such as mind/body, human/animal) that have traditionally structured law's understanding of its subjects, and bring into play new forms of vulnerable, precarious or cyborgian subjects, and the question of how they are produced and governed by the state and other bodies.

Emma Cave and Nina Reinach (Durham University) in their talk on "Patient-centred care now and then" discussed the developments in the law on informed consent and the impact that's had on the relationship between medicine, patients and the law. Exploring the rights-based approach in *Montgomery*, they contrasted the right to choose with rights to be consulted and to 'know'. With the aid of an historical vignette, and a personal story of family history that sets out a dilemma regarding the flow of information from doctor to patient, they considered how much has really changed and concluded that more change needed. They set out the principle of trust as paramount for any such future change.

Sylvie Delacroix (University of Birmingham) in her talk "At a cross-roads? The courts' shifting apprehension of the vulnerability at stake in the healthcare relationship." Sylvie took the case of *Montgomery* as a starting point for a theoretical analysis of the doctor-patient relationships. In the domain of healthcare, the focus on the epistemic vulnerability that characterises doctor-patient relationships has had the unfortunate effect of allowing questions relating to the appropriate disclosure of information (about known risks and side-effects) to occupy a lot of the conceptual space when it comes to articulating standards by reference to which medical judgment may lend itself to judicial oversight. This focus on information disclosure has in turn insidiously contributed to levelling down the qualitative difference between the responsibility of healthcare providers on the one hand and that of all expert

services providers on the other. The rationale for the disclosure of known risks and side-effects of medical intervention is indeed to address the knowledge asymmetry that characterises most doctor-patient relationships and to (supposedly) empower patients to make informed choices. Presented like this, the challenge at stake does not differ in any way from that which characterises the lay-expert relationship in a wide range of applications. Yet most people will have the intuition that there is an important difference between the choices that a healthcare provider is meant to empower and those at stake in a mountain expedition. The problem is that the courts' overwhelming focus on information disclosure has obscured what mere disclosure cannot achieve: empowering patients to retain some active involvement -and hence a sense of authorship- in the decision-making processes that are likely to shape their sense of self for some time to come. The latter empowerment aim may sound overly ambitious. I argue that it is no more so than a commitment to retain a meaningful, practice-relevant concept of professional responsibility. A shift away from mere epistemic vulnerability has the potential to contribute substantial changes to both the conceptualisation and the provision of healthcare in practice.

The session was concluded by a talk by Jose Miola (University of Leicester): who critically asked: "Patient Facing Medical Law: So Why Aren't I Happy?" Having previously argued for greater judicial recognition and engagement with the ethical issues in medical law, and a greater focus on the rights of patients instead of the duties of doctors, medical law seems to have delivered what Jose had hoped, particularly in the decision in *Montgomery*. Nevertheless, in his presentation he undertook a critical analysis of this decision and identified its shortcomings. He argued that the law has simply replaced one set of problems for another, that perhaps counterintuitively equally fails to protect patients and their interests. He also argued that we must now begin to subject judges to the same scrutiny that we used to impose on doctors.

SESSION FOUR: "OUT WITH THE OLD AND IN WITH THE NEW": A LENS OF HOPE?

The final session of the day, chaired by Citta Widago from the University of Birmingham, was probably the most eclectic of the day in terms of topics and methodologies covered by the speakers. It demonstrated the wide range of scholarly and disciplinary approaches associated health law and the diversity of possible avenues of its future development.

Richard Ashcroft (Queen Mary London): "The Utopian Functions of Health Law"

Richard explored health law through the lens of the Utopian vision set out in St Thomas Moore's book. He began by critiquing the approach taken to the

interface between law and personhood taken in the recent work of Foster and Herring (2017). He explored the satirical attempt made by Moore to outline a utopian vision and the implications for health law. Law and humanity can live in ordered set of laws. Would Health law produce an ideally ordered community? He provided examples, so for instance, the concept of informed consent projects the ideal doctor-patient relationship. It could be productive or indeed rhetorical in terms of conversation. He examined the implications as to whether human rights would be a better way to order things today.

Nicky Priaulx's presentation on "Glass Walls: The Relevancy of States and Strategies of Ignorance to the Future of Healthcare Law" argued for the centralisation of the 'unknown' within contemporary healthcare law. This is not a significant leap. Epistemological questions have long sat at the heart of legal studies, and increasingly such questions are woven into the fabric of healthcare law scholarship. A voluminous literature highlights the many epistemic fault lines running through the law: between law-in-the-books and law-in-action, embedded within legal concepts and standards, and the stories about human life that result. Nevertheless, what is unknown takes on a 'deviant' state, where the aim is to close gaps, capture the "real world", to render unknowns knowable to us as scholars, judges, legislators, patients and clinicians. While important, this presentation advocates a slight tilt in focus; moving away from ignorance as deviant, in favour of exploring its normality and regularity (Gross and McGoey, 2015). Illustrating how much of what is known is 'tacit', and how routinely we confront 'glass walls' of knowledge, she encouraged a direct confrontation with 'the limits of knowing' (Barnett, 2004). The aim was to open up quite different questions about the unknown, as well as to bring more clearly into view the strategies, structures, behaviours and methodologies of ignorance that populate our field.

Atina Krajewska was the last speaker of the day with her talk on "Health Law as a 'magic wand of visibility'?". In her talk she aimed to bring the sociological accounts of healthcare and law in the forefront of discussions and view the developments in health law through a functionalist and systems-theoretical lens. She suggest that - if reinterpreted and developed – they offer original insights and provide a very useful point of reference for creating systematic conceptualisations of health law in future. Theoretical debates about the nature and functions of health law often revolve around the idea temporal dislocation between health law and medical sciences. Health law is often perceived as a field that remains behind technological innovation, always trying, and inevitably failing, to keep up with advances in science. It is also often criticised for falling behind socio-political changes that render it inadequate, incoherent, or out-of-date. Much of this critique is undoubtedly warranted and necessary. However,

this paper aims to propose a different view of health law and analyse instances, in which it can release its jurisgenerative potential. Taking the controversial example of reproductive rights she argued that health law can be seen as a normative system that sheds light onto, often invisible (and almost always vulnerable), subjects allowing them to acquire visibility and subjectivity through the legal process. Focusing on the process of legal visibilisation, she demonstrated how health law in some instances has the ability to become means of resistance, mobilisation and citizenship formation. Consequently, she argued for the more discussions about the creative function of health law and its limitations as an important avenue of academic inquiry in future.

The response to the event and the discussions has been extremely positive. Many participants expressed their appreciation for the topic of the Workshop and said that discussions about the nature of medical, health law, and social care law were long overdue. Health law seems to be a discipline, which lends itself to theoretical debates and the development of philosophical and ethical concepts. Nevertheless, it remains very practical and has not fully engaged in self-reflection at a meta-level. A turn towards methodologies seems to be much needed and this is why the Workshop has been greatly appreciated. We could even say that it marked a form of "coming of age" point for health law as a discipline.

The success of the event and the need for further discussions was further reflected in the fact that we have been invited to prepare a special post-conference issue for *The Journal of Medical Law and Ethics*, which is going to be published in summer 2019. In addition, Edgar Elgar expressed their interest in pursuing a book project concerning the theme of our Workshop. As a result, plans for an edited collection entitled *Reimagining Health Law* are currently being developed. The collection aims to define the disciplinary boundaries and methodological approaches to Health Law and its future trajectories. The Workshop revealed great appetites for academic inquiry in this area and we are pleased we could begin the discussion and contribute to it at an early stage.