

SOLIDARITY IN BIOMEDICINE AND BEYOND

In times of global economic and political crises, the notion of solidarity is gaining new currency. This book argues that a solidarity-based perspective can help us to find new ways to address pressing problems. Exemplified by three cases studies from the field of biomedicine: databases for health and disease research, personalised healthcare and organ donation, it explores how solidarity can make a difference in how we frame problems, and in the policy solutions that we can offer.

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CAMBRIDGE BIOETHICS AND LAW

This series of books was founded by Cambridge University Press with Alexander McCall Smith as its first editor in 2003. It focuses on the law's complex and troubled relationship with medicine across both the developed and the developing world. Since the early 1990s, we have seen in many countries increasing resort to the courts by dissatisfied patients and a growing use of the courts to attempt to resolve intractable ethical dilemmas. At the same time, legislatures across the world have struggled to address the questions posed by both the successes and the failures of modern medicine, while international organisations such as the WHO and UNESCO now regularly address issues of medical law.

It follows that we would expect ethical and policy questions to be integral to the analysis of the legal issues discussed in this series. This series responds to the high profile of medical law in universities, in legal and medical practice, as well as in public and political affairs. We seek to reflect the evidence that many major health-related policy debates in the United Kingdom, Europe and the international community involve a strong medical law dimension. With that in mind, we seek to address how legal analysis might have a trans-jurisdictional and international relevance. Organ retention, embryonic stem-cell research, physician-assisted suicide and the allocation of resources to fund healthcare are but a few examples among many. The emphasis of this series is thus on matters of public concern and/or practical significance. We look for books that could make a difference to the development of medical law and enhance the role of medico-legal debate in policy circles. That is not to say that we lack interest in the important theoretical dimensions of the subject, but we aim to ensure that theoretical debate is grounded in the realities of how the law does and should interact with medicine and healthcare.

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FOREWORD

For many of us – those of us of a certain age, at least – our first meaningful encounter with the term *solidarity* was in the early 1980s, with the rapid emergence of the Polish trade union, *Solidarność*. From our perspective in the United Kingdom, it seemed almost ironic that one of the most prominent resistance movements in Eastern Europe should take *solidarity* as its banner in opposing a government which, one would have thought, should have itself been rooted in solidaristic ideals. Instead, in many communist countries, references to solidarity were abused to support grave injustices.

Of course, solidarity has a much longer, broader and even more complex history than this, as Alena Buyx and Barbara Prainsack make clear. But the upshot of its use in the context of the Eastern European upheaval was that solidarity was a term that belonged mainly to political philosophy and principally to politics of the left at a time when UK politics – along with the politics of much of the West – was beginning its long drift to the right.

Speaking from a UK perspective, even though we had in the NHS and the welfare state institutions that were arguably among the most solidaristic anywhere in the world, we became rather confused as to whether appeals to solidarity had moved beyond the bounds of respectable public discourse. It was a term that could be used in localised, interpersonal contexts, but there was some unease with its use at a societal level, given some of the practices that some political regimes had used it to justify. We did, nevertheless, look to other parts of Europe and admire the way with which *solidarité* seemed to permeate at all levels and signify fights *against* oppression and inequality, and *for* social justice. Or maybe that was just me.

In the meantime, *bioethics* was a youth, finding its way in a world that was losing many of its old certainties. We were no longer so confident that we should simply do what our doctor said. We were no longer sure that science would deliver progress that was an unqualified good. And we were no longer sure (if ever, indeed, we had been) that our interests as individuals and as communities and societies were adequately protected

by those in authority. But what had emerged in bioethics up until then had largely been based on an individualistic approach to ethics, whether through a human rights base in Europe, or an autonomy-based approach in the United States.

But increasingly, the idea that bioethics could and should engage a more public perspective took hold – a question of public good that is distinct from the protection of, or negotiation between, individual interests. The Nuffield Council on Bioethics (the UK's *de facto* national ethics council and one of the oldest such institutions), whilst never having committed itself to a particular approach or set of principles (rather, constructing an ethical framework for each case at hand) found itself in precisely this place – where individual and societal interests are both engaged – when it published its report on Public Health (2007).

Given the backdrop of solidarity as a concept used mainly in a political context, it should be no surprise, perhaps, that it was in the discussion of the underlying political philosophy that the Council first called on solidarity in support of its bioethical analysis. Actually it settled on the term ‘the value of community’ as expressing what it saw as the extended role of the classic liberal state: ‘... some speak of “fraternity,” others of “solidarity.” We prefer the term “community” which is the value of belonging to a society in which each person’s welfare, and that of the whole community, matters to everyone.’

Having moved in that direction, we then continued on the path. In subsequent reports – notably *Dementia* (2009), *Medical Profiling and Online Medicine* (2010), *Biofuels* (2011) and *Human Bodies* (2011) – solidarity was referred to and employed more specifically and directly.

So it was that in 2010 the Council felt that if we were to use solidarity as a core value and principle in our work, we should try to find it a more comfortable home in the wider lexicon of contemporary bioethics. We should try to find, or at least help to find, a more settled understanding of it, and not just at a conceptual level, but also in its practical application in bioethics. That is, to bring together its political meaning and its use as a matter of practical ethics, not least because ethics is intrinsically a political activity.

So we engaged Buyx and Prainsack in their respective roles – Buyx as the project lead on solidarity within the Council and Prainsack as a research fellow. Working in this way, and on a cross-cutting concept rather than a scientific or technological development, was a new departure for the Council. But it has been an extremely positive one – and we have since

repeated it in a similar fashion in looking at ‘naturalness’, another concept with a long history but an uncertain use in bioethics.

Their early work on solidarity, with an initial report for the Council in November 2011 and subsequent papers, contributed the first examination of the meaning of solidarity and how it can and should be used in concrete contexts. As Prainsack and Buyx themselves put it back then – uncovering its descriptive use(s) and its prescriptive role. The report generated a lot of debate and the Council was very pleased to see its international impact – academic citations, papers and conferences devoted to the report’s solidarity framework and, increasingly and probably most importantly, references in the policy world.

That Prainsack and Buyx have achieved all that is very much to their credit, as is the fact they have persisted in their work – listening, engaging, responding and adapting. Here, in this important new book, they have extended the theoretical analysis of solidarity in its descriptive and normative/prescriptive aspects, and have also extended the debate to new fields of application – health databases, personalised healthcare and transplantation/donation. So in addition to further refining their theoretical solidarity framework, their case studies highlight the potential of solidarity to be applied – usefully, and concretely – to pressing issues in biomedicine, both classical and emerging ones.

This book is a significant step in their work and in the contribution it makes to the wider academic and policy debates. The authors usefully show both what solidarity is, and what it does or can do, exploring complex issues of ethics and policy making in accessible language and always with a view to the real world. This is particularly striking with a term like solidarity, one with such a colourful history, and that has so often been (mis-)used for partisan political ends, or in vaguely idealistic ways. Giving solidarity firm meaning and divesting it of many of its past connotations enables academics, practitioners and policy makers to usefully work with the term in many different contexts. The case studies in the book offer clear examples, but there is still much further to go, more ways and places in which it can be employed. Indeed, the greatest achievement of Prainsack and Buyx’s work is perhaps to have broadened and also ‘restored’ the applicability of the concept of solidarity so as to give it purchase globally, and far beyond the realm of biomedicine.

I feel privileged to have played some small part in this, and pleased to have been associated with the work at its early stages before it developed into something with such real-world application. Which just about enables me to

contrive a conclusion in the form of a quote from Lech Walesa, the leader of *Solidarność*, and later President of Poland: ‘The supply of words in the world market is plentiful but the demand is falling. Let deeds follow words now.’ Well, this is a book, and so it is inevitably full of words, but it is notable that this important contribution extends from what the word solidarity *means* to what it *signifies*, whilst inviting a much more practical look at what it *does*.

Hugh Whittall
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