Putting the Morals Back into Medicine –
Emphasizing the ‘We’ over the ‘Me’

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I. Introduction

I am delighted to be able to contribute to the debate surrounding Barak D. Richman’s and Steven L. Schwarcz’s excellent article on “macromedical regulation.”1 It is a hugely important topic, and they have provided an equally important contribution to it. In this paper, I shall provide a very brief account of what I see as the theoretical underpinnings of their thinking. In essence, the concept of macromedical regulation involves the recognition that a health emergency such as we have seen with COVID-19 justifies the recategorization of the provision of healthcare from the private (in all senses in the United States) sphere to the public one.2 This is important, as it in turn signifies a move away from individual rights and choice and towards action designed to benefit society as a whole. In other words, it allows for a recalibration of focus from the “me” to the “we.” But, of course, this must be justified in some way, and that is the focus of this paper. I will argue that the concept of solidarity can be used as just such a justification, but also provide a cautionary tale from the United Kingdom to demonstrate the limits of that solidarity, and the key role played by reciprocity.

This piece is written from the perspective of English medical law. It is of course almost trite to say that our socialised system of medicine is very different to that in the United States, but it is also true to say that we have shared a legal trajectory that has tended towards the prioritisation of patient autonomy and choice.3 One of the features of the concept of macromedical regulation is that it

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1 See generally Barak D. Richman & Steven L. Schwarcz, Macromedical Regulation, 82 OHIO ST. L.J. 727 (2021).
seeks to solve a problem partly brought on by notions of autonomy and choice, which involve the prioritisation of the individual over the collective even where collective action may be of overall benefit to individuals. Indeed the COVID pandemic has brought this into sharp focus in relation to issues such as the allocation of scarce resources such as ICU beds and vaccines, where hoarding actively undermines the programme as new variants may develop in unvaccinated populations. This paper therefore seeks to propose a principle that might underpin the notion of macromedical regulation, and that is solidarity. As we shall see, this principle does not just impose on individuals a moral duty to act for the benefit of the collective but instead provides for reciprocal rights and duties that also impose limitations and obligations on the state as well as individual actors. I begin, however, by highlighting the problem with autonomy, before moving on to a contemporary example where the principle of solidarity might come in useful.

II. AUTONOMY, CONSUMERISM, AND MORALITY

English medical lawyer Charles Foster some time ago described what he labelled the “tyranny” of autonomy in medical law. He is certainly correct that it has become the dominant principle in English medical law. That this is so can be demonstrated in the landmark case of Montgomery v. Lanarkshire Health Board from 2015. This case, ostensibly about informed consent during childbirth, provided the U.K.’s Supreme Court with the opportunity to evaluate the whole of medical law, and it was one that they took with relish. In a judgment as much concerned about the future direction of medical law in its entirety as the case before it, Lords Kerr and Reed rejected paternalism outright:

[Social and legal developments...] point away from a model of the relationship between the doctor and the patient based upon medical paternalism. [...]. What they point towards is an approach to the law which, instead of treating patients as placing themselves in the hands of their doctors [...], treats them so far as possible as adults who are capable of understanding that medical treatment is uncertain of success and may involve

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4 See Richman & Schwarcz, supra note 1, at 732.
5 Id. at 767–68.
6 BARBARA PRAINSACK & ALENA M. BUYX, SOLIDARITY: REFLECTIONS ON AN EMERGING CONCEPT IN BIOETHICS 51, 70–72 (2011).
8 Jonathan Montgomery, Law and the Demoralisation of Medicine, 26 LEGAL STUD. 185, 186–87 (2006).
9 See generally Montgomery v. Lanarkshire Health Bd. [2015] UKSC 11 (appeal taken from Scot.).
10 See generally id.
risks, accepting responsibility for the taking of risks affecting their own lives, and living with the consequences of their choices.\textsuperscript{11}

So if paternalism was roundly rejected, what would replace it? In short, the answer was autonomy and a model based on patient choice:

\begin{quote}
\begin{itemize}
\item Patients are now widely regarded as persons holding rights, rather than as the passive recipients of the care of the medical profession.\textit{They are also widely treated as consumers exercising choices}: a viewpoint which has underpinned some of the developments in the provision of healthcare services.\textsuperscript{12}
\end{itemize}
\end{quote}

The final part of that quote is also perhaps worthy of note, in the sense that the court saw the provision of services as moving towards a more individualised, consumerist model as one of the reasons that the law should follow suit.\textsuperscript{13} However, as Richman and Schwarz note, in times of pandemic, individual components function less well than a coherent and integrated whole.\textsuperscript{14} Moreover, the danger with privileging choice is that it becomes a replacement for morality.\textsuperscript{15} This was recognised by Jonathan Montgomery, writing before the decision in Montgomery:

\begin{quote}
\begin{itemize}
\item The discipline of healthcare law is at risk of being transformed – moving from a discipline in which the moral values of medical ethics (and those of the non-medical health professions) are a central concern, to one in which they are being supplanted by an amoral commitment to choice and consumerism. In other words, that the morality is being taken out of medicine by legal activity.\textsuperscript{16}
\end{itemize}
\end{quote}

The most obvious example of this would be in relation to health data (although it might just as easily be applied to other issues such as compulsory vaccination), and indeed such a focus gets to the heart of the problem that macromedical regulation is created to solve.\textsuperscript{17} Data is something that is held by all healthcare providers but in different places and with few shared datasets.\textsuperscript{18} It is axiomatic to say that health data is extremely valuable.\textsuperscript{19} Not only can datasets aid researchers, they can also be aggregated from disparate sources to provide

\begin{thebibliography}{9}
\bibitem{11} Id. para. 81.
\bibitem{12} Id. para. 75 (emphasis added).
\bibitem{13} Id.
\bibitem{14} Richman & Schwarz, supra note 1, at 742–43.
\bibitem{15} Montgomery, supra note 8, at 186.
\bibitem{16} Id. (footnote omitted).
\bibitem{17} Id. at 187–89.
\bibitem{19} Id.
\end{thebibliography}
information that is far more powerful than when considered within their silos.\textsuperscript{20} It is precisely this sort of pooling of resources and knowledge that is required to defeat a virus such as COVID, and to be the most effective way of protecting populations.\textsuperscript{21} Put bluntly, the more information the better. Needless to say, a pure autonomy or patient-choice model of operating will by definition provide less data than one where consent is not required.\textsuperscript{22} Essentially, by providing choice for the individual, we harm the collective.\textsuperscript{23} While it does not necessarily follow that the state should simply be allowed to use the information without first gaining permission, it does at least encourage the question of whether data should be made available—even in the absence of patient consent—to be asked.\textsuperscript{24} Again, it is worth noting that this principle of sharing resources could also apply beyond data.

### III. TOWARDS SOLIDARITY

One compromise would be to consider the principle of solidarity.\textsuperscript{25} As Prainsack and Buyx note, solidarity is an emerging concept in bioethics, although it has its roots in classical social theory.\textsuperscript{26} This is not the place to enter into a detailed discussion into the precise nature of the principle, but Prainsack and Buyx provide what they term a “bare-bone” definition: “solidarity signifies shared practices reflecting a collective commitment to carry ‘costs’ (financial, social, emotional, or otherwise) to assist others.”\textsuperscript{27} They note that solidarity is more than an “abstract value,” and actually requires action, and we must be prepared to actually incur costs.\textsuperscript{28} In other words, the substance of the principle involves both a commitment to collective welfare and an acknowledgment that individuals must be prepared to incur personal costs in order to satisfy that commitment.\textsuperscript{29} However, there is one element to solidarity that is, in my view, critical to gaining the support needed to allow it to be introduced without coercion: reciprocity. Unlike the principle of altruism, for example, solidarity provides for an arrangement where people not only have a duty to the state, but


\textsuperscript{22} See KING’S FUND, supra note 20.

\textsuperscript{23} See id.

\textsuperscript{24} See id.

\textsuperscript{25} See William M. Sage, What the Pandemic Taught Us: The Health Care System We Have Is Not the Health Care System We Hoped We Had, 82 OHIO ST. L.J. 857, 859–60, 860 n.13 (2021).

\textsuperscript{26} PRAINSACK & BUYX, supra note 6, at 6–8.

\textsuperscript{27} Id. at 46.

\textsuperscript{28} Id.

\textsuperscript{29} Id.
the state also has a reciprocal duty to its citizens and residents. There is therefore a symmetry to the relationship between parties. While it is possible to argue that reciprocity is not an essential part of the principle of solidarity, others see it as a key part of it. The view of this author is that, if macromedical regulation is to work, the principle cannot properly function without it, as I demonstrate below. Nevertheless, this is aimed at providing a theoretical underpinning to how Richman and Schwarcz imagine that macromedical regulation might operate:

First, hospitals need to share information accurately and swiftly. At the outset of the pandemic, hospitals had no reliable mechanism in which they could determine the available capacity and constraints of nearby hospitals. Counties and states did not share ICU and ED statistics, and there were even fewer mechanisms to learn of shortages of specific components, such as ventilators or PPE.

The sharing of data and resources could be justified using this principle, and as I describe below this is something that has been proposed in the United Kingdom, but the story is a cautionary tale that highlights the importance of reciprocity to solidarity. In 2013, the U.K. government tried to introduce a system called care.data. The purpose was to “bring together health and social care information from different healthcare settings, such as GP practices, hospitals and care homes, in order to see what’s working really well in the NHS – and what we could [improve].” In other words, it wanted to access patient data, aggregate it, and use it to improve patient care. It should be noted that although the NHS is something of a monolith, patient data is spread amongst over 20 databases,
many of which cannot share information with each other. However, after a public outcry the plans were withdrawn, and it is the reason for this that is of interest to us. People were not concerned about the use of their data without consent per se, but rather that the data may be used outside of the NHS. A subsequent inquiry chaired by Dame Fiona Caldicott did not find fault with the philosophy behind the plan but rather noted that the public were unconvinced by the case for data sharing in the way that they feared that it would be shared.

There are two aspects worth noting. First, it would seem that the fears were not misplaced, as less than a year later we would learn that millions of NHS records were inappropriately sold to private insurance firms. Secondly, rather than asking people to opt into the scheme, the government proposed an opt out system, which led people to doubt their motives. The problem was in part, therefore, one of execution rather than concept. But it was also one where there were doubts about any quid pro quo. The Caldicott Inquiry referred to the NHS (and its records) as a “family,” and care.data failed because the suspicion was that the data would be taken outside of the family.

In the intervening years, the government has clearly learned nothing, as they have attempted to do the same thing again. At the end of May 2021, in the midst of the pandemic, a new scheme was announced: General Practice Data for Planning and Research (GPDPR). Almost identical to care.data in its intent to collect and aggregate data from GP practices, it also repeated the same mistakes and faced the same backlash. GP practices were given only 6 weeks to provide their patients’ data, and again the system was opt-out rather than opt-in. This in turn meant that patients, who had not received any significant information about this as there was no public awareness campaign, would have only that
time to opt out. The fear is that, again, it will be allowed to be shared outside of the family. Indeed, the pushback was such that the government agreed to postpone the deadline to September 2021.

So, what are the lessons to be learned from this? An obvious one is that trying to introduce such systems by stealth is unlikely to garner support and will almost inevitably fuel suspicion as to motives. However, it is also true to say that, when we drill down into the objections, they comprise the sale of or access to the data by commercial companies. What is not objected to is the use of the data to help improve NHS services for all, or indeed for research purposes where the NHS is the beneficiary. In other words, the scraping of the data is seen as permissible so long as it is kept in the family. This is where the principle of solidarity can help. If we need a justification for macromedical regulation, it can surely be found in the notion that we share a commitment to costs to assist others, and this is particularly the case where it will in turn lead to shared benefits. However, the issue of reciprocity is equally important in this regard. We are not being asked to share merely because it is the right thing to do (and without a quid pro quo). Rather, we are asking that people make data and resources available to others on the condition that they do the same, and that any future benefits are shared. The concerns over care.data and the GP DPR could be alleviated by a commitment to keeping any benefits “in the family.”

Thus data would not be sold to commercial firms for profits and instead used to provide a better service to all.

Macromedical regulation will, at least in part, rely on data, and the principle of solidarity, so long as it includes a requirement of reciprocity, goes a long way towards providing a strong justification for its use, even without consent. But it also provides a similar justification for use in relation to the sharing of physical resources—such as ICU beds, PPE, ventilators—as well. More than that,

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51 Id.
52 Id.
54 See, e.g., Malik, supra note 43.
56 Kamlana, supra note 18.
57 See PRAINSACK & BUYX, supra note 6, at xiv.
58 Id. at xv, xvii.
59 Kamlana, supra note 18.
60 Cf. Caldicott Report, supra note 41, at 5.
61 See Richman & Schwarcz, supra note 1, at 760; PRAINSACK & BUYX, supra note 6, at 43.
62 PRAINSACK & BUYX, supra note 6, at 43.
however, the public is unlikely to object so long as benefits are kept in the family, but even without that consent, a case can be made for the sharing of costs in order to share benefits.63 This would be on the moral basis that individuals have a duty to help others, but it comes with the significant mitigating factor that they can (and are entitled to) expect something in return.64

IV. Conclusion

The premise of macromedical regulation is that, in times of emergency, disparate entities engaged in healthcare might be brought together by “a reformed regulatory framework that enables, and sometimes requires, them to cooperate and coordinate appropriate surge responses.”65 This would have the effect of better allocating services and resources in order to fight a pandemic and, ultimately, both save lives and benefit the whole of society.66 This feels instinctively right, at least to this author. However, and as this Article has argued, we must also recognise that such an approach would be to go against the general trajectory of medical law, which has focussed on individual rights, “choice,” and an explicit nod towards consumerism.67 As the Article is written from a U.K. perspective, it is also perhaps worthy of note that this language feels, to us in the United Kingdom, like a desire to move more towards the system in the United States. Yet this Article has sought to provide a theoretical justification for macromedical regulation, noting both that, as Richman and Schwarcz make clear, the consumerist approach may not be efficient in emergencies68 and also that solidarity may provide an alternative approach.

Within this principle, however, this Article has also highlighted the importance of reciprocity and, in particular, the notion of keeping benefits “in the family.” This was done through the cautionary tales in the United Kingdom of the attempt to roll out the care.data system, and the equally clumsy attempt to harvest patient data through the GPDPR this year. The public’s lack of support was focussed not on the potential uses for research but rather the fears that the information would be sold to private companies. In other words, they wanted the benefits to be to the NHS and not beyond it. If we apply this to macromedical regulation, we might argue that the principle of solidarity would support the regulatory framework proposed by Richman and Schwarcz but that the requirement for reciprocity means that the benefits would be shared among patients in the United States, rather than being used to generate profits. In the face of a pandemic, this is surely something that we can all get behind.

63 See Caldicott Report, supra note 41, at 6.
64 PRAINSACK & BUXX, supra note 6, at 51.
65 Richman & Schwarcz, supra note 1, at 730.
66 Id. at 732.
68 See Richman & Schwarcz, supra note 1, at 729.