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Book review: *Solidarity in Biomedicine and Beyond*

Barbara Prainsack and Alena Buyx
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In an age punctuated by local and global crises (pandemics, natural disasters, and political calamities come most prominently to mind), and a seemingly ever-growing shift towards individualistic, consumerist behaviour (coded in part by a neoliberal socio-political ethos of self-responsibilisation), what principles can guide us in mitigating the attendant harm and risk, and in increasing our collective welfare? In this ground-breaking and inspiring book, part of the successful Cambridge Bioethics and Law series, Barbara Prainsack, Professor of Sociology at King's College London, and Alena Buyx, Professor of Biomedical Ethics at University of Kiel, offer a robust answer through their theoretical and analytical discussion of *solidarity*, which they first elaborated in a 2011 report for the Nuffield Council on Bioethics.¹ Prainsack and Buyx explain that their motivation for writing this book is to tout the benefits of solidarity, to offer clarity as to what it means (given its potential for vagueness and misuse), and to argue what it should "do" in the field of biomedicine and beyond. In other words, they aim to provide both further depth and normativity to solidarity. As Hugh Whittle observes in the book's Foreword, solidarity can have global purchase, well beyond biomedicine.

So it is in *Solidarity in Biomedicine and Beyond* that across eight well-written chapters, the authors develop the descriptive and normative contours of solidarity. In what follows, I briefly sketch the book's chapters and conclude with my overall assessment of its contribution to the relevant literature.

Prainsack and Buyx open their book by providing a brief history of solidarity as a concept and as a "project". They observe that whilst solidarity is gaining currency in the academic literature, it remains a heterogeneous concept, meaning different things to different people. This said, tracing the term's history,

¹ Barbara Prainsack and Alena Buyx, *Solidarity: Reflections on an Emerging Concept in Bioethics* (Nuffield Council on Bioethics, 2011).

they note that many of the essential elements of solidarity have persisted across time, including: a sense of being “bound together” through, for instance, sharing similar objectives or circumstances; mutual assistance and help, particularly in situations of hardships; symmetric relationships between those engaged in solidary practices at the moment of enacting solidarity (i.e. despite other parts of their lives not being equal or even similar); and a link to both individual and collective well-being (p. 4).

In Part I (“Theorising Solidarity”), Prainsack and Buyx tease out the key themes, ideas, and concepts from different cognate disciplines that have influenced their conceptualisation of solidarity, including work from Durkheim, Weber, and communitarian, feminist, and postmodern philosophy. Observing that solidarity first entered the Western political domain in the late eighteenth century, fuelled by French revolutionaries who also used the closely related term *fraternité* to refer to a feeling of political community, Prainsack and Buyx proceed to develop their definition of solidarity as “enacted commitments to accept costs [financial, social, emotional or otherwise] to assist others with whom a person or persons recognise similarity in a relevant respect” (p. 42). As they explain, “similarity in a relevant respect” means that “one has something in common with the person that matters in a specific situation” (p. 53). Solidarity rests on commonalities; contrariwise, the concept of charity rests on differences.

Prainsack and Buyx unpack their definition to ably carve out a distinct conceptual space for solidarity, distinguishing it from concepts such as reciprocity, empathy, and altruism, and to put flesh on its conceptual bones. Doing so not only provides intellectual benefit, it also helps build solidarity’s usefulness for application to policy contexts in biomedicine and other areas. Prainsack and Buyx chart several key points about solidarity’s definitional contours (pp. 45-48):

- (1) Solidarity is most fruitfully understood as something that is enacted, and not as an abstract value, normative ideal, or inner sentiment. This means that it requires some external manifestation that is apparent to others.
- (2) Analyses of solidarity need to take into consideration concrete practices, policies, and their contexts.
- (3) Context is of crucial importance in understanding whether a given practice can be regarded as solidaristic.
- (4) Solidaristic practices often include values and knowledge that cannot be fully articulated nor assessed according to parameters of rationality.
- (5) Because solidaristic practice is always contextual, it draws attention to the relation between the actor and her human, natural and artefactual environments. This means in consequence that people's interests are also typically shaped by concern for others, and that we cannot distinguish neatly between self-interested and other-directed action. This distinguishes solidarity from concepts such as altruism.

As a distinctly original contribution to the field, Prainsack and Buyx distinguish between three "tiers" of solidarity. Tier 1 delineates interpersonal solidarity (i.e. manifestations of individual willingness to carry costs to assist others). Tier 2 delineates group solidaristic practices (i.e. manifestations of collective or shared commitment to carry costs to assist others). Tier 3 delineates solidarity enacted on a legal level (i.e. solidarity institutionalised in the form of contractual, legal, or administrative norms). The authors explain that whilst the "lower" levels of solidarity "often exist without the 'higher' levels, these higher levels have typically – but not always – been preceded by lower levels. In other words, solidaristic norms and provisions at tier 3 have often emerged out of initially more informal practices of solidarity at the inter-personal (tier 1) or communal or group level (tier 2)" (p. 57). However, they also observe in a

footnote that "...individual practices from lower levels which entail choice are a vital precondition for solidaristic laws and regulations" (p. 58). If this is the case, one wonders what happens when tier 3 solidarity does *not* emerge from practices at tier 1 or 2. Would Prainsack and Buyx describe such laws and regulations as illegitimate as they do not accurately reflect the cultural norms and social practices of the given society?

In Part II ("Solidarity in Practice"), the authors apply a solidarity-based perspective to several case studies in biomedicine. Whilst the three main chapters in this second Part focus on biomedical fields, they do not ignore the "beyond the biomedical" element, as we will see in their concluding Chapter 8.

In Chapter 5, solidarity is applied to health databases. A substantial number of health databases today collect and process a tremendous variety of data from the personal, clinical, and public domains, and at a much higher volume than ever before. This raises new challenges that extant ethical and regulatory frameworks cannot resolve. Indeed, Prainsack and Buyx argue that extant governance practices for biobanks and health databases dichotomise personal and common benefit, placing too much emphasis on enhancing individual autonomy (manifested most starkly through increasingly lengthy consent forms) whilst simultaneously trying to maximise collective benefit through enhanced data collection and processing.

Using a solidarity-based perspective, they posit that governance practices should focus attention instead on shared societal benefit and shared societal responsibilities, which would treat data sharing, information privacy, and data protection as both collective and personal goods. This means that databases built on solidarity should be designed to serve public interests (not serving exclusively for-profit goals) and aim to create social value. Databases should disclose their commitments to prospective participants in the form of a mission statement. Principles of veracity (i.e. an attitude of respect towards data donors as equal

partners of those running and hosting databases) and transparency (i.e. an openness to public scrutiny) should drive database governance practices. This would mean in turn that databases should strive to make research findings at both personal and aggregate levels available with as few barriers as possible. For their part, individuals should not contribute their data merely because they expect a personal benefit (e.g. payment or direct reward).

Significantly, Prainsack and Buyx argue for a shift in governance practices from risk management to harm mitigation. They argue that risks should be acknowledged as an ever-present feature in biomedical practices. To better or most honestly reflect a willingness of participants to accept costs when engaging with databases, they suggest an emphasis on devising strategies for harm mitigation in cases where actual harm occurs. As they explain:

We thus suggest that the owner or funder of a database governed according to the solidarity model sets aside a particular sum each year, or a particular proportion of the total funding, to pay into a 'harm mitigation fund'. [...] The explicit function of the harm mitigation is to provide financial support in situations when there is no legal right to compensation (or when the compensation obtained through legal means is not considered sufficient) (pp. 120-121).

In Chapter 6, Prainsack and Buyx show how the notion of personalisation in medicine and healthcare can, in principle, bring the personal and the collective levels closer together.² Four examples are provided of how the idea of personalisation can be employed to work towards a kind of healthcare that seeks to foster solidarity: 1) giving more importance in medical decision-making to people concerning aspects of their bodies and lives that are important to them; 2)

² See also Barbara Prainsack, *Personalized Medicine: Empowered Patients in the 21st Century?* (NYU Press, 2017).

increasing the ability and support for patients to donate their data to research projects; 3) the necessity to maintain or create public healthcare systems that exclude as few people as possible; and 4) incentives for lifestyle changes, e.g. “nudges” (and here, the authors argue that nudges are compatible with a solidarity-based perspective when they are targeted at the *general* population and avoid stigmatising particular groups).

In Chapter 7, Prainsack and Buyx examine several proposals to increase the number of organ donors through the lens of solidarity at its different tiers: live organ donation between strangers (tier 1); priority allocation of organs to members of a club of registered donors (tier 2); and switching from an opt-in system of post-mortem organ donation to an opt-out system (tier 3). Focusing here on their tier 1 discussion, the authors disagree that, despite the language used by regulators such as those in the UK,³ organ donation to strangers is defined by altruism. “Altruism reflects the idea that somebody’s action is *either* self-serving or other-regarding, with altruism being solely other-regarding,” they argue. “Such a dichotomous understanding between self- and other-regarding practice is incompatible with the relational understanding of personhood that underpins our concept of solidarity...” (pp. 153-154). Prainsack and Buyx claim that the mislabelling of such donations as “altruistic” might discourage some potential donors who are more strongly motivated by solidarity. They suggest therefore that policymakers should promote non-directed live donations explicitly as (also) acts of solidarity; they need not be “purely” other-regarding.

The authors conclude in Chapter 8 with an assessment of the value of solidarity, namely its potential for 1) unlocking and shaping debates; 2) having

³ See e.g. Human Tissue Authority, *Code F: Donation of Solid Organs and Tissue for Transplantation* (HTA, 2017), which uses the terms “directed altruistic donation” and “non-directed altruistic donation”, the latter of which denotes the form of donation where a healthy living person donates an organ or part of an organ to an unknown recipient.

practical utility; and 3) emphasising the importance of background conditions for solidaristic practice and policy to function and flourish. Closing the circle on their book's title, they also discuss where solidarity can go beyond biomedicine. Examples they flesh out include the "sharing economy", exemplified by couchsurfing and temporary flatsharing, and online skill- and goods-based exchange networks. This said, Prainsack and Buyx are careful to emphasise that people's recognition of similarity does not come out of nowhere; background conditions and social practices that emphasise similarity must be in place for solidarity to flourish. As they write, "...if we want to have more solidarity, and if we want to keep the level of institutionalised solidarity that we already have, then we need to foster social practices that emphasise similarity" (p. 184).

In sum, *Solidarity in Biomedicine and Beyond* is a brilliant book – one that will be referred to again and again by bioethicists, policymakers, regulators, and academics across a variety of disciplines. It capably builds on their 2011 Nuffield Council on Bioethics report, and signals the birth of a fully fleshed out and vital ethical concept and practice. After reading this book, one may well feel inclined to conclude that this is an old "new" ethical principle that should be increasingly instantiated in our individual, social, and political lives.