OPEN LETTER

Biomedicine, self and society: An agenda for collaboration and engagement [version 1; referees: 2 approved]

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Abstract

The commitment of massive resources – financial, social, organisational, and human – drives developments in biomedicine. Fundamental transformations in the generation and application of knowledge are challenging our understandings and experiences of health, illness, and disease as well as the organisation of research and care. Coupled with the accelerated pace of change, it is pressing that we build authentic collaborations across and between the biomedical sciences, humanities and social sciences, and wider society. It is only in this way that we can ask and answer the penetrating questions that will shape improvements in human health now and in the decades ahead. We delineate the need for such commitments across five key areas of human and societal experience that impact on and are impacted by developments in biomedicine: disease; bodies; global movements and institutions; law; and, science-society engagements. Interactions between ideas, researchers, and communities across and within these domains can provide a way into creating the new knowledges, methods, and partnerships we believe are essential if the promises of biomedicine are to be realised.

Keywords

Social Science, Humanities, Biomedicine, Disease, Bodies, Global Health, Law, Engagement

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Introduction

Promise of new knowledge of health and disease and new means of preventing and treating illness—as well as the economic and commercial benefits such innovations might bring—animates biomedicine from top to bottom: from government policy makers and public and private funders, to individual doctors and researchers. In short, promise underpins the massive commitment of resources—financial, social, organisational, human—that drives biomedicine (Brown & Michael, 2003). With such enormous resources in play, it is unsurprising that developments in biomedicine are having a profound impact across many areas of human life and experience, the dynamics of which need urgent and rigorous attention (Rose, 2007). What biomedicine delivers is not always the same as what it promises: it is often only with the wisdom of hindsight that we are able to separate promise from what seems like inevitable hype (Feiler *et al.*, 2017). An enterprise as vast as biomedicine is bound up with multiple, and often conflicting institutions and interests, which pull it in different directions; research and development rarely progress in a straight line, and innovation is fraught with unintended consequences. Small wonder, then, if the outcomes of biomedical investment often differ from what was promised, with implications for society that go far beyond simply delivering new means of prevention and treatment.

The difficulty in foreseeing exactly how local, national, and global biomedical initiatives will pan out is not a reason for resigned acceptance of whatever those programmes deliver, however. On the contrary, it underscores the need for close and continuing societal engagement and involvement with biomedicine, from the initial formulation of promising research programmes, right through to the design and implementation of new health interventions, and at all stages in between. Efforts to promote such engagement and involvement are still in their infancy, and it is far from clear what forms they might ultimately take and how they might influence innovation trajectories and health experiences. Yet, if biomedicine is to develop in ways that respond most effectively to wider societal needs, it is imperative that such efforts continue in a spirit of open-minded collaboration and informed critical reflection.

As growing numbers of scientists and clinicians, funders and policy makers recognise, researchers in the social sciences and humanities possess knowledge and skills that equip them to play an invaluable role in informing, facilitating, and critiquing these endeavours (Pickersgill *et al.*, 2018). Hence, for instance, the Wellcome Trust's own commitment to fund research in the humanities and social sciences, "to bring new perspectives and ways of thinking to the historical, ethical and cultural contexts in which medical science takes place" (Wellcome Trust, 2010, p. 17). Likewise, the increasingly common practice of inviting social scientists and humanities scholars to participate in technoscientific projects, especially but not only in biomedicine, with the aim of securing improved governance and social acceptability. Yet, such collaborations bring novel challenges, as participants from within and across different disciplines try to work out their respective roles in the business of shaping technoscience (Balmer *et al.*, 2016; Callard & Fitzgerald, 2015; Frickel *et al.*, 2016). Still, the need for such collaborations is paramount: biomedicine is reshaping our lives in multifaceted ways, through interrelated transformations of knowledge and practice, research and care, institutions and forms of governance, and individual and collective identities. Only by working across disciplinary boundaries, and with patients and publics, can we begin to comprehend these transformations in all their complexity, in ways that will enable us to engage constructively as well as critically with the dynamic relationships between science, public health, and healthcare; the shifting geographies of global, national, and local institutions; and the lived experiences of individuals and social groups around the world.

Transformations of biomedicine, self and society

There can be no simple prescription for how to build such collaborations, but we can at least begin to map the kinds of questions and issues they might most fruitfully seek to address. Social scientific and humanities research into the socio-cultural system that is biomedicine has already produced a wealth of insights into the nature and meaning of biomedical science and healthcare in societies. Drawing on such work, we can identify five interconnecting domains of individual and societal experience which provide fertile ground on which to cultivate new inter- and transdisciplinary enquiry. We now reflect on these and some of the issues they bring into focus.

Disease

Contemporary developments in biomedicine not only challenge long-accepted ideas about the nature of particular diseases; they also raise more general questions about just what counts as disease. This has enormous implications also for the organisation and delivery of health care, and for the sociotechnical organisation of biomedical science, it will have profound impact on individuals' experience of health and illness. In the case of cancer, for instance, increasingly 'personalised' understandings of tumour aetiology are fragmenting existing classificatory schemes and exacerbating clinical uncertainty, even as they offer the hope of new and more effective treatments (Keating & Cambrosio, 2011; Kerr & Cunningham-Burley, 2015). At the same time, population research into biomarkers in cancer and other conditions is leading to new categories of pre-disease risk, bringing new classes of 'patients-in-waiting' under medical management (Aronowitz, 2015; Timmermans & Buchbinder, 2010). In psychiatry, the objectivity of established clinical tools for diagnosing mental disorders is being questioned by research funders, and there are calls for fundamental revision of existing diagnostic categories in the hope of driving therapeutic innovation for mental ill-health (Pickersgill, 2014). Multi-dimensional approaches to population studies of experiences associated with psychiatric disorder are complicating understandings of the boundaries between normality and pathology. In society more widely, debates over disability, normalcy, 'naturalness' and enhancement further problematize concepts of disease and therapy, across a range of contexts spanning mental, physical and reproductive health and biomedicine (Nuffield Council on Bioethics, 2015). Meanwhile increasing costs, earlier preventive interventions and an ever-widening range of ways in which

individuals seek to access biomedical technologies only add to the uncertainties about what counts as health, illness, and disease, and who benefits or suffers from those designations.

Together, these developments raise fundamental questions about the nature of disease, about who has the epistemic authority to label it as such, and about the normative and political significance of the disease concept itself. Biomedical research alone cannot answer these questions; indeed, as the relationship between research and clinical practice becomes increasingly blurred, the issues only become more complex. Close engagement with social science and humanities research, as well as patients and their families, will help us all to navigate the fraught borderlands between health, illness, and disease in ways that best address the needs of individuals and populations.

Bodies

As a key site of biomedical intervention, the human body is increasingly chemically regulated, technologically augmented, and digitally rendered. The diverse connections between individuals and bodies and body-parts is intensely mediated by technical, social, and legal instruments (Crawford, 2014; Flear *et al.*, 2013; Hoeyer, 2013; Mol, 2008; Quigley, 2018). In the case of emerging innovations such as 3D bioprinting of replacement organs, for instance, this raises questions around justice, social stratification, and regulation (Vermeulen *et al.*, 2017). Other technoscientific developments in genetics and genomics, pharmaceuticals, nanotechnology, and biotechnological devices have implications for individual experience and collective representations of embodiment. The changing relationship between subjectivity and bodily identity and integrity potentially destabilises established ontologies of human beings. New vulnerabilities are created (Oudshoorn, 2016), contributing to a unique form of 'biomedical nemesis' (Haddow, forthcoming; cf. Illich, 1974). Simultaneously, practices such as 'biohacking' and the 'DIY Bio' movement challenge who should be permitted to create hybrid artificial-organic bodies and techno-scientific identities, pushing the limits of current medical and legal understandings of control and responsibility. The increased datafication of the human body is arguably reducing aspects of the physical human form to inexhaustible datasets (Parry & Greenhough, 2017), signalling the prospect of data flowing freely within and beyond the biomedical sphere, amplifying social and ethical concerns around the privacy and security of individuals, groups, and populations (Pink & Lanzeni, 2018).

Research in the social sciences and humanities provides a rich legacy of concepts and methods for understanding and accessing human embodied experience, challenging the mind-body dualism once inherent to 'Western' medicine. Contemporary research is beginning to shed light on how the possibilities of bodily repair, replacement and regeneration affect the ways in which individuals experience themselves as embodied beings. Fundamental questions about why changes to the materiality of the body alter subjectivity are brought into sharper relief (Haddow *et al.*, 2015). We need such forms of interdisciplinary research to apprehend fully the complexities of radical amelioration and enhancement (Pickersgill & Hogle, 2015). Careful and critical thinking with scientific researchers and clinical practitioners about how biomedical expertise and experts themselves (actively or otherwise) are informing and structuring shifting meanings and, indeed, what counts as embodied experience, is required.

Global movements and institutions

Accelerating global movements of people, goods, data, and capital have led to new geographies, both of health, illness, and disability, and of technoscientific practice (Bozorgmehr, 2010; Keane, 1998). Despite commitments to globalisation and increased investments worldwide, the uneven spatial and socioeconomic distribution of disease and ill-health continues (Clinton & Sridhar, 2017). With an exponential increase in funding for global health initiatives, and the creation of a global health technocracy, local concerns are increasingly over-written by transnational flows of ideas and resources, especially in low and middle income countries (Adams, 2016). Health priorities and practices are typically constructed through universalistic discourses of science and economics (Sridhar, 2011), ascribing value to individuals and their bodies and calculating the impact of disease in ways that elide local meanings, needs, and values (Anand *et al.*, 2004; Leach & Tedros, 2014).

Models such as the Global Burden of Disease project funded by the Bill and Melinda Gates Foundation mediate the traffic between local and global understandings of disease. We need to critically interrogate the relevance and limitations of such models for priority-setting in health policy. At the same time, there is a too common tendency to frame financially poorer nations solely as beneficiaries of healthcare knowledge, as opposed to producers of it (White *et al.*, 2014). Without attention to the different roles that low income countries can, should, and do play with respect to the production of biomedical and other health-related knowledges and the actualization of new biotechnologies, we may fail to confront the problems of global scientific as well as health justice (Chan *et al.*, 2017). Novel, spatial analyses of contemporary biomedicine must be attentive to the consequences of its glocalization (Robertson, 2012)—the ways in which biomedical ideas, actions, and artefacts not only circulate internationally, but are simultaneously localised and particularised. In so doing, they also need to break away from path-dependent normative and empirical approaches and foci that all too often rehearse the colonial tropes they ostensibly aim to undermine. Collaborations between biomedicine, global health, social science, and humanities combining local and global contexts, that also engage populations across different nations, will help propel a more radical and transformative agenda for global public health.

Law

Law and legal processes and their associated institutions are present throughout biomedicine, from intellectual property regimes to regulation of clinical research to protection of individual and collective patients' rights. All too often, law is perceived to place barriers along the route from science to health; for instance, by obstructing research or by creating artificial boundaries between different jurisdictions or sectors of research (Academy of Medical Sciences, 2011). However, such perceptions fail to recognise that law also plays a constitutive role in

biomedical research and practice (Cloatre & Pickersgill, 2014). This is not least through helping to establish norms and standards for scientific knowledge production, material and intellectual exchange, constructive participation, and effective ethical review that lead to social value (Ganguli-Mitra *et al.*, 2017). For instance, regulatory impasse may be overcome through interdisciplinary, iterative engagement with scientific communities to design and deliver adaptable systems of research governance (Laurie *et al.*, 2012).

A deep focus must now be paid to how law functions as an intrinsic element of biomedical culture, including its role in the processes of developing frameworks for pre-emptive regulation that enable the emergence and consolidation of socially acceptable and accountable biomedical science, as well as in enabling the stewardship of biomedical researchers through regulatory environments (Laurie *et al.*, 2018). Examining how regulatory stakeholders construct legality around their actions and with what consequences (Richards, 2015) demands a blending of social scientific and humanities insights to understand how regulators and regulated actors (including scientists and clinicians) co-produce adaptable regulatory practices while raising questions about the letter of the law itself (Stephens *et al.*, 2011). Whether, where, when, and how law decelerates biomedical development and application, or acts as an accelerator of multiple stakeholder-desired change, demands subtle and careful attention to the multiple effects of law and legal processes. Put briefly, we need far deeper understandings of law as a lived experience within biomedicine than we possess at present.

Science-society engagements

Participation and partnerships are increasingly mobilised in the production of biomedical research, the development of health-related policy, and health care delivery (Involve, 2005). From individual patient involvement through to population-wide engagement, multiple sites of participation characterise the nexus between biomedicine, healthcare organisations, social groups, and individual experiences of health and illness. Politicians, scientists, clinicians, and wider publics can have complex relationships with the processes, practices, and outcomes of engagements. For instance, different forms and instances of engagement can be viewed variously as an asset and barrier to policy development, health research, and service delivery across clinical and public health. Matters are further complicated by the increasing blurring of patienthood and participation in (for example) data-intensive population studies, where patients become at once producers of commercially valuable data as well as consumers of healthcare (Prainsack, 2017). Funders and research regulators may also intervene to shape the relationship between research, engagement, and participation; for example, by requiring public and patient involvement as an essential element of research strategies and projects.

Social scientists have led a critical understanding of public engagement with respect to science and its governance (Irwin & Michael, 2003; Jasanoff, 2003; Kelty & Panofsky, 2014), and many have been key to shaping the institutional contexts and individual experiences of engagement with biomedicine (Aitken *et al.*, 2016; Aitken *et al.*, 2018; Haddow *et al.*, 2007). Parallel developments in bioethical thinking have tracked evolving paradigms of research ethics and the changing role of participants with respect to science (Emanuel & Grady, 2007). Understanding and shaping effective participation requires both social scientific appreciation of the expertise that non-specialists can bring to shaping science and its regulation (Cunningham-Burley, 2006; Kerr *et al.*, 2007), and bioethical reflection on how best to reconceptualise the normative dimensions of participation (Chan & Harris, 2009; Chan *et al.*, 2011). Explorations of how publics are currently interpolated within biomedicine, and with what consequences, are necessary in their own right (TNS, 2015). We also have to ask difficult and potentially uncomfortable questions about whether, how, and when different groups should engage to maximise the public good.

Conclusion

The need to comprehend and interrogate contemporary transformations in knowledge, health, and experience is vital. Inequalities persist despite enormous advances in prevention and treatments; new technologies of research and care are troubling accepted ideas about the human body, health and disease; and the expansion and proliferation of citizen engagement and partnerships bring both opportunities and challenges for biomedical science and healthcare. These pressing issues demand imaginative and innovative responses. As a considerable body of scholarship implies (Cunningham-Burley, 2006; Irwin & Michael, 2003; Kerr *et al.*, 2007; Webster, 2002), close engagement between diverse communities is required to shape, direct, and, indeed, personalise biomedical research in ways that deliver the greatest social benefit. Research within and between the medical social sciences and humanities is vital. So, too, are novel partnerships between scholars in those fields with scientists, clinicians, and policy-makers. Researchers across academic disciplines could do much more to work effectively together in order to understand the complexities inherent in biomedical science, and to promote the kinds of social as well as technical change that will deliver equitable promotion of health and wellbeing locally, nationally, and globally. They also need to engage enthusiastically, deliberatively and openly with wider publics and civic society. Ultimately, we need a new social contract between biomedicine and society that better serves the aim of improved health and well-being for all. If we are to achieve this, it will not be enough to challenge one other from the security of our own disciplinary perspectives, whichever they are, nor simply to try to reconcile our different disciplinary commitments. Together we need to rethink biomedicine from the ground up.

Data availability

No data is associated with this article.

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This is a very thoughtful and timely contribution to the debate on interdisciplinary collaboration in the health domain. The authors emphasise the important role of "authentic collaborations across and between the biomedical sciences, humanities and social sciences, and wider society" to create new knowledge in biomedicine. They then identify and discuss five domains which they argue are of particular relevance for such collaborations (and particularly impacted by them in turn).

I consider this Letter a timely and substantive intervention into debates, funding programmes, and policies shaping knowledge production in this field. In the following section I will share a few thoughts that the authors may, or may not, take up in their further work on this topic.

1. Underpinning the argument of the authors is the assumption that relevant biomedical knowledge can no longer be disciplined into clearly delineated domains of expertise and practice. This is a profound point that could be made more explicit. What are the reasons for this? The authors mention “fundamental transformations in the generation and application of knowledge [that] challenge our understandings and experiences of health, illness, and disease as well as the organisation of research and care”. But what are these transformations? For example, how are we to understand the attempts by researchers and policy makers to bring research and healthcare (e.g. in precision medicine), individual- and population-level data and interventions (e.g. in precision public health), and the social and the biological (e.g. in epigenetics) closer together? What types of cross-disciplinary and cross-domain collaborations made this possible, and what types of collaborations do these new convergences require?
2. The names of the five domains that the authors identify - disease, bodies, global movements and institutions, law, and science-society engagements - are labeled in traditional biomedical and global health terminology. To reflect the spirit of the cross-domain and cross-disciplinary collaboration that the authors highlight in their Letter, it may be better to focus not only on disease but also on illness, not only on bodies but also on people, and on the collaboration between global and local institutions.
3. As critical scholars have pointed out, much of the literature conceptualises collaboration as *transactions* between bounded independent entities. An alternative ontology would be to conceive collaboration as *interactions* between entities that are related to each other through shared interests, stakes, (and, in case of human actors, also shared identities). When reading the

Letter I was wondering what ontology underpins the authors' call for more "authentic" collaboration. What makes collaborations authentic? What types of actors and relations does authentic collaboration require?

4. The authors' point, on p4, that "there is a too common tendency to frame financially poorer nations solely as beneficiaries of healthcare knowledge, as opposed to producers of it" is a very important one, and one that perhaps deserves even more emphasis and elaboration. How can collaboration have a positive impact on changing these dominant frames? I also wonder how collecting data from people in low- and middle income countries (LMIC) would be considered by the authors: Does this count as healthcare knowledge creation on the side of people in LMIC countries, or does it increase the new social division between data givers and data takers? Or both?
5. As a reader of this Letter I would love to hear what the authors consider good examples for the types of collaborations that they call for. Perhaps it may be possible to name a few examples in the concluding section, or to give an example in each of the five domains.

Is the rationale for the Open Letter provided in sufficient detail?
Yes

Does the article adequately reference differing views and opinions?
Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?
Yes

Is the Open Letter written in accessible language?
Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?
Yes

Competing Interests: One of the authors of this letter, Martyn Pickersgill, contributed a chapter to a Handbook that I co-edited last year: Pickersgill M. 2018. The value of the imagined biological in policy and society: Somaticizing and economising British subject(ivitie)s. In: Gibbon S, Prainsack B, Hilgartner S, Lamoreaux J (eds). Handbook of Genomics, Health & Society. London: Routledge. P99.

Referee Expertise: Regulatory, social, and ethical aspects of biomedicine and bioscience

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

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This is a timely and important Open Letter inasmuch as current developments in diverse areas of biomedicine, and the life sciences more generally, disturb conventional understandings of the body/medicine/society relationship. The article rightly points out that as boundaries - of the body, of disease, of care, of responsibility and so on - become more blurred new forms of collaboration across the biomedical sciences, social sciences and humanities is required. New complexities call for new collaborative endeavour.

The various sections provide very useful, concise overviews of how these disturbances shape different domains of biomedicine, with a solid body of supportive references to support the argument. Each of these domains pose specific challenges to biomedicine if it is to be socially robust, that is one that combines innovation with accountability. The debate in recent years over 'responsible research and innovation' is clearly of relevance here.

It is then extremely important to show how in practice this interdisciplinary collaboration might be made possible, and thereby move from a position of critique (key though that is to any engagement) to one of co-production. Here there is some unevenness in the article, with perhaps most clear recommendations on what might be involved seen in the concluding observations in the 'Global movements and institutions' and 'Law' sections.

To unpack this comment a little more, we can note that in many ways the increasing differentiation of disease classification systems and the subsequent disruption of the normal/abnormal boundary is to be welcomed by the social sciences/humanities who have long seen hard borders as problematic (as noted especially in the section on 'Bodies' in regard to multiple meanings of 'embodiment'). At the same time, how social science then helps people - patients/populations/clinicians/biomedical researchers - to create more valuable and socially robust ways of handling disease and illness becomes an ever greater challenge as a result, especially if we are to participate in the co-production of meaning and practice. Complexity of practices and how these can be managed by patients, clinical staff and carers, for example, become of central importance (eg in regard to the complexities of end-of-life care). So here social science needs to address how to handle three interrelated but discrete elements - the complexity of phenomena, the personal difficulties experienced by people and uncertainty over possible futures.

The challenge for those who take home the very important message of this article is how to find sites where this form of knowledge is possible and what a new community of practice combining disciplines would look like. The article concludes by a call to 'rethink biomedicine from the ground up'. Given the programmatic nature of this piece presumably we need to also rethink social science/humanities 'from the ground up' too. Perhaps the best place to do this is through identifying trans-disciplinary sites where new methodologies can be co-created for building a shared understanding, especially when seeking to shape policy and practice[1]. The challenge in particular is to somehow bridge between what has been called 'critical interdisciplinary research' and 'instrumental interdisciplinary' research[2-3] - that is, challenging conventional understanding in a constructive way. The authors themselves have shown how this is possible in their own prior work. Perhaps an indication of the challenges they faced and how they were resolved would have helped to point the reader, new to this debate, in the right (interdisciplinary) direction.

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Yes

Does the article adequately reference differing views and opinions?
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Are all factual statements correct, and are statements and arguments made adequately supported by citations?
Yes

Is the Open Letter written in accessible language?
Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?
Partly

Competing Interests: No competing interests were disclosed.

Referee Expertise: Sociology of Science and Technology and the biomedical sciences

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.