

Special Issue of Health Care Analysis: Translational Bodies—Ethical Aspects of Uses of Human Biomaterials

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Since the beginning of history, the human body has been the point of departure for human understanding, both of ourselves and of the universe. The body in life and in death, before and after birth has been the subject of traditions and taboos, of art and science, of research and litigation and is now often subject to extensive regulation as human material becomes the focus of technological advances in biomedical science. Our understanding of the human body, and indeed humanity, is informed by concepts of human personhood and concepts of the mind. The body is fundamental to human experience and both shapes and is shaped by wider institutional and cultural forces: bodies and embodiment also demand sociological analysis of its past, present and possible future if we are to generate innovative understandings and useful policy outcomes.

This collection of papers, as well as those presented in a special issue of *Law, Innovation and Technology* [1] emerged from a three-day workshop ‘Translational Bodies’ held at Monash University’s Prato Centre, Italy in April 2014. The workshop was the culmination of work under the Wellcome Trust Strategic Programme on the Human Body: Its Scope, Limits and Future. The programme, with the human body as its unifying focus, was specifically designed to draw together multiple disciplinary and international perspectives to inform the field of bioethics—and policy developments relating to new biomedical technologies—about understandings of the human body and their interactions with scientific and

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technological advances, law, culture and social relationships. These issues are at the very centre of human bioethics.

Building on established, multidisciplinary research groups by pursuing new research directions, the research of the programme, and more specifically that in the papers presented here, significantly contributes to shaping the field of biomedical ethics. Through bringing together different disciplines including law, philosophy, biological science and social science (especially medical sociology), with consequent influence on public policy; development of new methodologies; and substantially increasing capacity for training and future interdisciplinary research; the programme was able to deliver a major contribution to knowledge and to create a new axis of research excellence in biomedical ethics that actively combines cognate disciplines to tackle fundamental moral issues.

The specific areas of research across the programme and the biomaterials strand in particular were carefully chosen to deliver a systematic analysis of the normative values surrounding the human body. Furthermore, they were designed to ask how these are constructed in different contexts and across different sectors and social groups; because the answers to questions of what we ought or ought not to do, and hence what developments should or should not be permitted, will continue to critically influence the course of human advancement and therefore of the embodied human experience.

The papers contained within this special issue reflect the multi-disciplinary nature of this programme and the work within its human biomaterials research strand. The authors approach the issues from a wide range of disciplinary perspectives and their work frequently connects with ideas and themes across the programme's other strands (genethics, reproduction, enhancement, and methods in bioethics). As with many of the programme's outputs, these papers contribute insights relevant to both academic understanding and practical policy development.

The human body retains a fundamental centrality to our understanding of ourselves and our relationship—both individual and collectively—to the world. Our bodies as they are and as they might (and will) become are the focus of advances in various—often converging—fields, which are increasing the significance of human biomaterials both as external objects (e.g. tissues, organs) and as shapers of our internal world and relationship to others; not just as end-users of technology but at all stages of development. A prime example being the focus of this collection—the use of human biomaterials in medical and scientific technology—and, further, the new enhancement technologies which may modify the body and challenge our understandings of what it is to be human. An in-depth analysis of our role as human actors in this process is vital for our understanding of ourselves and our place in an ever-changing technological world. The unifying perspective given by taking the human body as our focus gave coherence to the entire project and ensured that it was grounded in and produced research that not only is, but will be widely perceived to be in future, relevant and important.

Expanded availability and understanding of genetic information for example, and the ability we now have to alter that information or the ways that it works via gene editing techniques and an increased understanding of epigenetic triggers for gene expression may alter understandings of family relationships—particularly parent

and child—and so legal developments relating to uses of genetic information and material can not only shape the uses of technology but also the nature of those relationships and trust within them. So the law may redefine or simply reinforce perceptions of the significance of genetic relatedness in families where it applies to mitochondrial replacement therapy [3] or it may alter attitudes towards genetic ‘harm’ when conceiving a child [5].

Similarly, other important social relationships and trust within them can be deeply affected by changes in understanding and use of biomaterials. This includes: our relationship with ourselves and the significance of consent and control to our identity were we to be subject to genetic enhancement [2]; our medical relationships as smart implantable devices remove control from both patient and physician, and perhaps the associated sense of responsibility too [4]; the potential breakdown of trust between science and its publics because narratives about past practices do not necessarily apply appropriately to current standards [6]; and that the trust needed for scientific cooperation between states is damaged by concentration of benefits in a few countries [7].

In all the papers presented here, there is a close relationship seen between the pursuit of improvement and/or protection of human health, technological advances, and policy responses; as well as the development or reinforcement of particular social and ethical norms around both bodily materials and particular technological advances. In Griffith’s paper we see how regulatory and policy responses to mitochondrial replacement therapy appear to be reinforcing ‘traditional’ concepts of parenthood and family relationships; while the technology itself (and ARTs in general) would seem to be fundamentally altering “what relatedness means in the context of reproduction”, so that while technology can have radical potential, social and political forces tend towards conservatism. Wilson’s paper meanwhile provides an understanding of the history of medical and scientific use of human tissue; and how current problematisation of past practice overlooks changes in professional and social contexts as well as the impact that political agendas and ethical concerns emerging from other areas of medical practice can have.

DeGrazia’s paper, while resisting the common enhancement/therapy distinction in its definition of enhancement, does go on to explore the significance of other priorities in public health. It queries whether—even where a genetic enhancement is proven safe and effective—the potential benefits to health would weigh sufficiently against the expenditure of public resources that would most likely be necessary for its development. Relatedly, Haddow et al.’s paper explicitly presents health as a driver for the use of implantable smart devices and, through exploration of individual experiences, highlights how they can shift medical relationships—both between the patient and clinician and the individual and their body—and create problems around perceptions of responsibility, control and vulnerability.

Returning to the issue of public health more explicitly, Stanton’s paper recognises the role of the law in protecting this but questions the appropriateness of applying criminal and civil legal penalties to transmission of infectious disease; and raises concerns about the implications of extending this to genetic transmission, including possible loss of trust in social relationships. The paper shows how law (and its application) is both shaped by and forms a response to scientific

developments—in this case in understanding of and ability to identify genetic transmission. Rhodes' paper takes a fresh approach, using public health goals as a framework for understanding how states should approach the international management of human genetic material; and noting that the current limited consideration of and response to this issue combined with the context in which the ownership/control of genetic material more generally is managed, can lead to undesirable outcomes.

In some of the papers we can see technology become a powerful driver of law and policy and of change to social relationships, but we also learn to question the extent to which the existing order is reproduced [3], whether established priorities ought to change [2], and whether existing legal and regulatory structures are capable of adapting to scientific advances without creating significant gaps, tensions and fragmentation [3, 5, 7].

Change and adaptation are key themes throughout the papers, but they also highlight that we should be aware both that what seems like change may simply be re-production of traditional structures and relations; and that we shouldn't ignore past changes e.g. in definitions, in acceptability, or in what is viewed as problematic or normal practice when trying to understand current concerns. Collectively, the papers illustrate that there is co-existence of both fundamental change and processes of continuity and reproduction as the newness of technology meets persistence of political, legal and social structures and relationships. Bioethics, law, politics, science and society may interact on an immediate basis, but they also tend to shift, change and evolve on very different timescales.

Narratives of power and powerlessness emerge, alongside issues of control and concerns about exploitation. We are led to ask, to what extent should the law seek to control reproductive choices (and their outcomes)? [3, 5] Does control by others of 'our' biomaterial necessarily create vulnerability and powerlessness? [2, 4, 6] What forms of control over human biomaterials are suited to meeting public health goals? These questions highlight the connection of the issues presented herein to long-standing ethical concern about how to balance individual and group interests.

Overall, a key point made by the papers, individually and collectively, as well as the full programme on the Human Body: Its Scope, Limits and Future, is the importance of combining a variety of perspectives to better understand the contexts—historical, sociological, legal, political, scientific, and more—in which interactions between technology, law, policy, and society are re-creating and re-inventing our understanding of the human body; the materials derived from it; and of the ethical responses to their increasing use and utility.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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