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Editorial: Towards a sociology of donation Rebecca Dimond¹, Laura Machin² and Lucy Frith³

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Rapid developments in technology have continued to extend possibilities for isolating and exchanging body parts, marking donation as an increasingly significant practice in the 21st century. In recent years we have witnessed heightened political and sociological interest in the donation of body parts and products, such as organs, gametes and embryos, blood and tissue, and in related activities of procurement, processing, banking and distribution. In this editorial we highlight the pressing need to develop a sociological framework to encompass this wide range of activities and to theoretically conceptualise how these practices assemble as a form of donation and what commonalities and disjunctions they present. It is now time to recognise the sociology of donation as a significant sub-discipline within sociology. This themed section is one of the first collective attempts to lay the ground work for what a sociology of donation might look like.

Donation has a long history, with intended and unintended consequences, spanning the medical and non-medical sphere, and has existed, and in some parts continues to exist, outside of any formalised system. Yet the sociology of donation has been disjointed, with analysis focused on the activities around the donation of specific organs and tissue, rather than developing donation as a cohesive concept. Developing a sociology of donation could focus on the following vital sociological questions: How is donation conceptualised and what kinds of relationships does it produce? How are human body parts and products valued? How does our understanding of donation illustrate the relationships we have with our bodies and its products? How is donation practiced and regulated within local and international contexts? The meanings and understandings surrounding 'donation' are not neutral and it is only when we start from this perspective that we are able to gain insight into the status, acclaim and power that exists within the 'donation' system. For example, the creation of the first Organ Donation Towns in the North of England to drive local communities to join the organ donor register, or media reporting the 'first' face or womb donation, each construct a trajectory containing multiple histories and futures.

Developing a sociology of donation suggests several key themes. The first are theoretical and historical perspectives. It is important to consider the continuities and discontinuities with past practice, and what is controversial or normalised and no longer visible within debates. There is an important classificatory turning point for example, in how and when some tissue and body parts become valuable or waste, reminding us that the value of human tissue in its re-use is continually negotiated. We see this when we consider the purity and messiness of donation. Donation can generate risks for those receiving, as well as donating, body parts and products. Moreover the restrictions surrounding who can be a donor, to whom, can be extended or relaxed under different circumstances.

The second theme is relationships formed through donation. For almost fifty years, Titmuss (2018[1971])' 'gift relationship' has been crucial in characterising the imagined relationship between donor and recipient. But does 'the gift' continue to provide a useful framework for understanding donation when it is clear that the ways and means and reasons for donation are multiple and complex? We have seen in the recent example of mitochondrial donation how new technologies can pose a challenge to social, legal and ethical frameworks for managing relationships between donor and recipient (Dimond and Stephens 2018). The cultural importance of genetic relationships is highlighted by the changes in anonymity policies in the case of egg, sperm or gamete donation, linked to assumptions about who has the right to know, and the right not to know. As Frith et al. (2018) amongst others have highlighted, we also need to pay attention to the experiences of recipients, donors and their families in how these relationships are imagined and enacted (and see Ashall and Hobson-West (2017) for how donation practices extend beyond human relationships).

The third theme we have identified is choice and control, highlighting the ways in which 'choices' are restricted or facilitated, and by whom, for whom, and in what ways. We can also think about how those choices are supported, the role of counselling and what kinds of pressures are placed upon individuals in terms of personal and collective motivations to donate. And with increasing choice (for some) about how we manage and

negotiate our bodies, which kinds of donations, and what kinds of uses might be constructed (and advertised) – are they treatment, cure or enhancement? The final theme is trade and consumption, drawing and extending Waldby and Mitchell's (2006) 'tissue economies' which recognised how tissue and their biovalue are produced and circulated. Here we can think about how value is measured, and how justifications of (non-)payment to some types of donors, vary according to what is donated, for what purpose, and by whom. And of course, in a global economy we need to remember how the value of tissue, body parts and fluid can be determined by, and contested through, coercion, exploitation and ownership.

Each of our four articles in this section challenge and expand our thinking around the sociology of donation. The first is Shaw's article titled 'Altruism, solidarity and affect in live kidney donation and breastmilk sharing'. Shaw contributes to the sociology of donation by taking an interdisciplinary approach, drawing on fields such as the sociology of morality and affect studies to strengthen its analytical power. She draws on ideas of tissue economies to explore altruism and gift relationships, and how biovalue and new forms of 'bio-intimacy' are produced. This work is important because it draws on her own work biography; qualitative research she has conducted over the last 15 years, particularly interviews with live kidney donors who have donated to known people, some 'altruistic' donors who have donated to unknown people, and women who have donated or shared their breastmilk with known people and strangers. By acknowledging the experiences of those who donate to friends and strangers, but also the involvement of for-profit organisations, Shaw recognizes how the reasons why people donate are constructed and intimately entwined by and with policies which aim to protect donors from coercion, and in some cases, prevent monetary gain. As Shaw highlights, donors are required to present themselves in particular ways in order for their act of donation to be considered legitimate and for the 'right' reasons.

The second article in this section focuses on an often unacknowledged issue within discussion of donation, highlighting donation as a gendered practice. Kent, Fannin and Dowling's article titled 'Gender dynamics in the donation field: human tissue donation for research, therapy and feeding' uses gender as an analytic lens, to explore ethical valuation of risk and moral hierarchies which they say varies according to the different tissues at stake and contrasts these with universal notions of altruism. Their work is interesting because of the breadth of areas they study. They focus on five different sites (donations for different purposes) to explore the expectations and norms around donation practices: aborted foetal tissues, placental tissue, umbilical cord blood, breastmilk and blood. Drawing on Waldby's work around 'biovalue', this paper explores the different social, cultural and ethical assessments about human tissue and its risks. Over these five sites, the authors consider how the hierarchy of value and donation practices are shaped by societal assumptions about motherhood and maternal responsibility. They highlight how the substance and value of tissues are co-produced through the relationship between 'maternal and foetal bodies', which challenges ideas of ownership and belonging, and of self and other and highlight how 'waste' products relating to pregnancy can be subsequently identified as valuable, yet the practices remain rooted to gendered ideas around pregnancy. They say that differences in practices and values of donation cannot just be reduced to biology, but they are shaped by 'gendered concepts of maternity/parenting, responsibility and risk'.

The third contribution is Boylan, Locock and Machin's work titled 'From waste product to blood, brains and narratives: developing a pluralist sociology of contributions to health research'. Their work provides a broad overview of the sociology of donation, particularly focusing on what donation means within health research. Boylan and colleagues explore the different ways in which people contribute to health research, drawing on a wide range of studies to identify the significance of language, hierarchy of value, informational value, narratives (as donation), coincidental donation, and associated issues of rights, consent and benefit. In writing this article, their aim is to reconceptualise donation by moving away from focusing on the donation of body parts and fluids to recognising alternative kinds of contributions. Overall their article acknowledges the complexity of donation, calling for a pluralist approach to the sociology of donation which recognises the range of motivations and the 'shifting boundary' between donation and exchange, and acknowledging, particularly in the research context, how a donation to research can represent an ongoing relationship between researcher and participant.

This themed section concludes with an article by Nordqvist, 'Un/familiar connections: On the relevance of a sociology of personal life for exploring egg and sperm donation', offering a valuable contribution to the limited research on the experience of donors. Nordqvist applies a sociology of personal life, highlighting how focusing on connectedness can bring new insights about the practices, and implications of donation. Nordqvist first of all considers the work involved in negotiating genetic relationships. Donors are often part of a broader family network, where each member can present different and potentially competing claims and responsibilities. Secondly, Nordqvist considers relationality, one example of which is how relationships with the recipient are imagined or embodied within every day practices. Finally, through the concept of 'the intimate body', Nordqvist

recognises how donation involves the management, and potentially, the crossing, of sexual and intimate boundaries. Nordqvist's work is particularly interesting because it recognises how everyday aspects of our personal lives can be shaped through donation practices, and it notes how further research is urgently needed to understand how these experiences are shaped through sexuality, class, race and gender.

This themed section is part of a wider remit to acknowledge and develop the sociology of donation. The British Sociological Association's Deconstructing Donation Study Group was established in 2014, and it supports an annual 'Deconstructing Donation' conference held in the UK, attracting interest from researchers and practitioners in sociology, law, bioethics, history, medicine, criminology and anthropology. Our current understanding of sociological aspects of donation draws on broader sociological concerns such as the sociology of the body and social relationships more widely. We are able to draw on a strong history of sociological exploration which has thus far shaped the field, but we recognise and welcome the opportunity to learn from other fields. The study of donation is enhanced by incorporating insights from other fields and developing interdisciplinary approaches to this area will be a fruitful direction for future research.

Overall, this themed section is an exposition of the current state of the art in knowledge around donation to establish the sociology of donation as a distinctive sub-area of sociology. Ultimately, it invites future researchers to address the timely question - is it possible to develop a theory of donation which can account for such a wide range of current practices, involving diverse body parts, actors and technologies? And with such rapid developments in medical and digital technologies, we need to keep thinking about what the future of donation might hold, and how we, as sociologists, can make sense of the challenges it presents.

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References

- Ashall, V. and Hobson-West, P. (2017) 'Doing good by proxy': human-animal kinship and the 'donation' of canine blood. *Sociology of health & illness*, 39, 6, 908–22.
- Dimond, R. and Stephens, N. (2018) *Legalising mitochondrial donation: enacting ethical futures in UK biomedical politics*. Cham: Palgrave Pivot.
- Frith, L. Blyth, E. Crawshaw, M. and van den Akker, O. (2018) Secrets and disclosure in donor conception. *Sociology of Health & Illness*, 40, 1, 188–203.
- Titmuss, R. ((2018[1971])) *The gift relationship: from human blood to social policy*. Bristol: Policy Press.
- Waldby, C. and Mitchell, R. (2006) *Tissue economies: blood, organs, and cell lines in late capitalism*. Durham, M.C.: Duke University Press.