**A moral economy of transplantation: Competing regimes of value in the allocation of transplant organs**

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**# Introduction**

The chronic shortage of transplant organs has long been recognised as a problematic area for medicine and for medical ethics. The considerable attention it has attracted, not only from clinicians but also from academics, the media and policy makers, has focused in the most part on the supply of organs and issues such as the role of consent and the possibility of using incentives to increase levels of donation. Yet the allocation of organs to patients needing transplants is, perhaps, the more pernicious problem. With long waiting lists for transplants, problems of rationing and allocation will never entirely vanish, even if the supply of organs were to greatly increase. The technicalities of transplant surgery require systems of allocation that take account of the biological characteristics of donor and recipient ([Forsythe 2009](#_ENREF_13)). For some patients the absence of transplantation will mean certain and almost immediate death, while others can be maintained for longer periods through medication and interventions such as dialysis. Allocation of transplant organs is a technically complex and morally fraught process: it is value-laden through and through.

Normative approaches to the distribution of organs span two poles. Equality of access is exemplified by lottery, while success-based utilitarian approaches emphasise tissue matching and graft survival to achieve maximum survival benefits across the population. Positions between the two must be negotiated on the basis of increasingly complex medical, social and moral claims ([Weir 1995](#_ENREF_36)). Disciplinary preoccupations have also become apparent in discussions: bioethicists such as Wilkinson ([2003](#_ENREF_38)), Cherry ([2005](#_ENREF_9)) and Taylor ([2005](#_ENREF_33)) have advocated markets and economic incentives grounds of autonomy and self-ownership, while medical evidence, objectivity and transparency, are the central concerns of clinicians ([Wiesner, Edwards et al. 2003](#_ENREF_37)). The views of the general public are complex and fail to produce a usable consensus; opinions depend upon age, gender and social situation ([Neuberger, Adams et al. 1998](#_ENREF_22); [Wilmot and Ratcliffe 2002](#_ENREF_39)). Ironically, individual patients are heard least, and given little option regarding the organ they will receive, although there is an argument that elderly patients should be allowed to choose an available, sub-standard organ rather than queue for a high-quality one ([Freeman 2007](#_ENREF_14); [Shapiro 2007](#_ENREF_31)).

Popular opinion matters to policy, nonetheless. Clinicians are aware of the need to balance public demands and clinical evidence, ensuring a supply of donated organs through the maintenance of trust and positive relations between the medical practice and the general public. As James Neuberger ([1998: 979](#_ENREF_22)), director of the U.K.’s transplant service writes:

‘The processes which will, in effect, result in the denial of a life-saving procedure for many individuals, need to be explicit, objective, just, equitable, transparent and retain public trust and confidence. Therefore, robust processes for both selection and allocation need to be developed and implemented.’

Keeping the public happy may be difficult. General principles for allocation among the public include: maximum benefit; the moral worthiness of recipients; preference for younger recipients; and medical urgency ([Tong, Howard et al. 2010](#_ENREF_34)). Prejudices, for example towards those suffering alcohol-related disease, are also clearly shown in public responses ([Johri and Ubel 2003](#_ENREF_15)). However, the public does value notions of fairness and equality of access over and above measures of outcome, emphasising just distribution even when the result will be a decrease in lives saved by the organs available ([Ubel and Loewenstein 1996](#_ENREF_35)).

Though there is no consensus on principles, these disparate approaches do share a conception of moral decisions as prior to, and ontologically separate from, the actual *processes* through which organs are allocated. In the early years of transplantation, it was left to surgeons to enact the requirements of policy and distributive frameworks as best they could ([Weir 1995](#_ENREF_36)). Where external expertise was brought to bear on problems of allocation it has tended towards practical solutions of the technical complexities: Alvin Roth’s work on organ exchange, for which he was awarded the Nobel Prize, is exemplary in this respect ([Roth, Sönmez et al. 2005](#_ENREF_28)). His ‘New England clearing house’ is an algorithmic matching device that enables single donations to trigger chains of paired or three-way transplants, helping many to receive the much needed organs. Roth ([2007](#_ENREF_27)) presents a thoughtful analysis of moral repugnance as a constraint on market design, urging economists to treat repugnance as a genuine dis-utility, not to be washed away by sight of increased welfare gains. Even Roth, however, in concluding that kidney exchange can offer many of the benefits of markets without provoking repugnance, does not fully recognize the complex relationships between notions of value and the material mechanisms that embody them.

Central to this volume, on the other hand, is the recognition that values are neither prior to, not separate from, their material and organisational settings. As knowledge is enacted in practice ([Latour 1987](#_ENREF_16)), so valuation is seen as an active and on-going process embedded in specific practices, tools and architectures. Value depends upon the epistemic – what is known and what is worth knowing. As Dussauge et al. write in the introduction, the enactment and stabilisation of values are a central part of what there is to explain ([Dussauge, Helgesson et al. 2014](#_ENREF_12)).

The present chapter explores the articulation of value through the technical apparatus of organ allocation in the U.K.’s National Health Service (NHS). The chapter documents the development of centralized, computer-driven allocation systems for kidneys, and a ‘thought experiment’ to achieve an optimum result for liver allocation.[[1]](#endnote-1) These developments are a consequence of the growing recognition of transplantation as a mainstream surgical procedure and a reliable treatment for renal and liver failure. The change in the status of transplantation has greatly increased the demand for transplants, swollen waiting lists and led to an ‘organ donation push’ that has recast organs as a public resource, donation as an ‘opportunity’ and donor bodies as having rights akin to the living.

And yet, for all this scarcity, an organ is of little value without a body. It may not be bought or sold. It has no price. But it can offer someone a renewed life, depending on the existence of a suitable recipient, and its value comes about through use: its steady work in the body of the patient. Even a poor quality kidney might have value, should a recipient be found who would accept it. Thus allocation becomes a crucial moment in the production of value; the value placed on transplant organs by scarcity, by supply and demand, is made visible only by the matching process. Allocation protocols render the interdependence of organ and recipient calculable and malleable; it is through matching processes that the relations of value are discovered.

Notions of value and exchange this allude to a moral economy of a kind, less developed or overtly economic than those in cadaveric procurement ([Anteby 2010](#_ENREF_2)) or cord blood ([Brown, Machin et al. 2011](#_ENREF_6)). Nonetheless, values are more than subjective measures, containing ‘normative presumptions about the ways in which markets should be organized’ ([Reinecke 2010:564](#_ENREF_26)); there exists a reflexive relationship between transcendent values, valuation enacted by material devices, and the professional norms of healthcare workers. Transcendental norms are embedded in cultural antecedents and discourses ([Boltanski and Thevenot 2006](#_ENREF_4)) surrounding the practice of transplantation. There we find the virtues listed by Neuberger (1998): clarity, objectivity, justice, equity, transparency. Shadows of politics are also visible in the pure calculations. Political choices motivate priority to paediatric recipients or those from ethnic minorities, or a move towards a utility model emphasising younger recipients to increase survival benefit across the population ([Shapiro 2007](#_ENREF_31)). Finally, there are the professional ethics of practitioners, manifested as a commitment to care and personal involvement with patients.

This chapter shows how the implementation of allocation devices radically reconfigures each realm of value: the meaning of good clinical practice is transformed as equity and utility are enacted and themselves translated ([Latour 2007](#_ENREF_19)) through models, simulations and algorithmic protocols. At the same time, frames of valuation overflow, reclassifying certain behaviours as resistance or unethical practice. The protocols not only dictate who receives, but also *what matters*. Through the empirical site of organ allocation, the chapter extends the contribution of this volume in unravelling the technical, epistemic and economic embeddedness of value in the life sciences – emphasising the instability and flux of moral arrangements, a moral economy ([Daston 1995](#_ENREF_11)) perpetually unfolding and being worked out.

The chapter will first of all consider the earliest aspects of allocation and the development of a discourse of transplant practice at a national level. I will then discuss the development of a formal allocation process for kidneys that took place in the late 1990s and early 2000s, before examining a current ‘thought experiment’ in the liver transplant sector. The chapter considers notions of resistance to these reforms, and then discusses the enactment of value in the moral economy of transplantation.

**# Institutionalising transplantation and transplant organs**

Transplantation is a relatively new medical technique, and just as great efforts have been placed into increasing the sophistication and success rates of surgery itself, so much attention has been focused on the problems of queuing and allocation that attend it, particularly since the mid-1990s ([Weir 1995](#_ENREF_36); [Persad, Wertheimer et al. 2009](#_ENREF_25)). Nonetheless, the rapid expansion of transplantation in its early years resulted in a historically dependent patchwork of protocols and policies, varying both geographically and across transplant specialisation (from organ to organ).

The United Kingdom is divided into eight transplantation zones, each centred on one or two large teaching hospitals (for example the John Radcliffe in Oxford, Addenbrookes in Cambridge, or the new Royal infirmary in Edinburgh). As recently as the mid-1990s, transplantation for all organs operated at a local level. Each centre maintained a list of patients awaiting transplantation, and when a donor became available in a zone, local surgeons were responsible for retrieving organs and allocating them on a discretionary basis according to observed clinical need and suitability of matching. Guidelines did not prescribe any way of assessing clinical need. In the case of liver transplants, for example, matching considerations centre solely on similarity of donor and recipient size and blood group; surgeons and consultants were therefore left with considerable discretion in their allocation.

If, as was frequently the case, there was no suitable recipient, organs would be offered to other centres on a rota basis, centrally managed by the national health service, and monitored by a ‘balance of exchange’ where centres were expected to finish the year having supplied as many organs into the system as they had received. The balance of exchange was managed locally by the nurse coordinators. This kind of scheme still exists in the case of certain organs and certain categories of donor, and has certain advantages, according to Research Scientist 3: it allows the autonomy of local centres, it is quick to implement and easy to maintain, and is excellent at optimising activity at a centre level.

Kidneys were the first organ to be regularly transplanted. In the late 1960s and 1970s relatively unsophisticated retrieval techniques and tissue typing meant that all kidneys were dealt with on a local basis. Subsequently, a nationwide system was established to distribute one of each pair of kidneys retrieved, while the other was maintained by the hospital. Inevitably, this led to concerns from peripheral units that patients in the large hospitals, where retrievals were conducted, had a higher chance of receiving a kidney (Surgeon 2). By the mid-1990s it was apparent that there were great differences in waiting times and the accompanying mortality rates from centre to centre. Increasingly, surgeons found this situation unacceptable. In the mid-1990s, Surgeon 1 became chair of the Kidney Advisory Group, the committee responsible for oversight of renal transplantation.

‘When I took over as a member of that group and then taking over as the chair of [the advisory group for kidney transplantation], I became particularly interested in allocation of organs, and particularly allocation of kidneys. And I asked for the statisticians [within the NHS] to give us a snapshot of allocation and the effects of allocation policy across the United Kingdom and it was clear to me that there was inequity of access…both in terms of patients getting onto a waiting list, and once they were on waiting list, the allocation of a kidney to those individuals.’ (Surgeon 1)

These discrepancies ([Oniscu, Schalkwijk et al. 2003](#_ENREF_24)) are in many cases still unexplained, and may relate to exogenous factors such as demographics and education of the local population, as well as surgical procedures and the willingness of surgeons to take risks in using less than perfect organs in cases where there may still be a marginal benefit to the transplant recipient (Consultant 1). Nonetheless, they were considered cause for action.

Surgeon 1’s statement makes explicit what he considers to be the primary concern of any rationing in allocation mechanisms in organs: equality of access, understood in terms of geography, ethnicity and social demographics. Behind his statement lies an increasing awareness of transplant organs as a public resource: transplantation had become a standard surgical procedure that could be deployed to tackle increasing levels of renal failure and public health problems. Scientific advances, making the impossible achievable, and then routine, force a consideration of the ethical concerns involved in a new everyday practice. In the US, the Task Force on Organ Transplantation, established in the late 1980s, held that donated organs should be considered public resources, held in trust by surgeons and procurement organizations ([Childress 1989](#_ENREF_10)). In the UK, the Human Tissue Act (2004) wrote the same claim into statute. European presumed consent goes further still, upholding the state’s claim to the bodies of the deceased. Recasting organs as the raw material for an everyday medical procedure has clear ramifications. As a public resource, organs must be shared equitably and in a transparent manner. Consultant 1’s most strident objection to the local system is its opacity, in that definitions of clinical need may differ from one centre to another, and too much is left to the judgement of individual surgeons.

The decision to recognise transplant organs as a national resource has ramifications in many related areas. In intensive care, for example, where resources are inevitably rationed, the discourse of transplantation – ‘the organ donation push’ (Consultant 2) – has seen the rights and wishes of would-be donors taken increasingly seriously, even after their death. A would-be donor may be admitted to intensive care, and despite being clearly beyond recovery, may still be cared for:

‘if it was that patient’s express wish that they would be an organ donor, it is in that person’s best interest to provide them with a period of critical care, knowing that they’re not going to survive, but knowing that they wish to be a donor, and that there is a secondary benefit, other people who get the organs will benefit.’ (Consultant 2)

Despite a transformation in the understanding of transplant organs, transplantation as a medical practice exists in a liminal position, half institutionalised, and half gift economy. The provision of an intensive care bed for the maintenance of a cadaver, even for a few hours, may come at the cost of treating another patient. Surgical retrievals, while funded in part by direct payment from a central fund (Surgeon 2) still need to work around the routines of a busy hospital and not to ‘piss off’ (Nurse 1) the everyday users of surgical spaces. Despite the obligation of hospitals to provide theatres, staff and anaesthetists, transplantation may sometimes meet with objections. Nurse 1 recalled one anaesthetist’s reply to a request for help: ‘I didn’t do my training to come and anaesthetise a dead person’.[[2]](#endnote-2) The NHS has countered by creating specialised roles such as the CLOD (Clinical Lead on Organ Donation) whose task it is to build institutional support for transplantation; developing transplantation is a job that depends greatly on public relations and relationship building (Nurse 1; Consultant 2). Meanwhile, surgeons are recast as entrepreneurs who are required to submit business plans to departmental heads bidding for resources – theatre, nurses, and anaesthetist – and then claw back costs from peripheral units whose patients are being treated. What counts, in practice, is often down to the energy and political skills of individual practitioners.

Dealing with a national resource forces a discussion of what constitutes fairness, a discussion played out in negotiations between medical practitioners of all levels of seniority. For example, admittance to the liver transplant waiting list is determined in one hospital by a large meeting attended by many of the fifty-strong transplantation group: surgeons, doctors, nurses, social workers and transplant coordinators. ‘Utility’ and ‘equity’ are concepts that excise these meetings, as are transparency and a constant battle between number driven medics and the holistic, pastoral view taken by carers and social workers. The result is a sophisticated and philosophically literate medical workforce: transplantation is, as Surgeon 1 notes, ‘ethics in practice’. Utility, equity, and compassion are the concepts that most of all frame subsequent discussions on the allocation of organs: what, exactly, does fairness mean?

**# Engineering fairness in kidney allocation**

Surgeon 1, aided by colleagues from the advisory group, instituted a programme of reform that that was intended to systematise the allocation of kidneys in the United Kingdom, ensuring equity of access across the nation. The effect of these changes has been to move from discretionary allocation to a situation where ‘every kidney has a patient’s name on it’ (Surgeon 2).

The advisory group settled upon tissue matching as the guiding principle for the new allocation scheme. This arrangement focuses on the utility and efficiency of the transplant, guaranteeing the highest level of success and post-operative function for each kidney. In broad terms the 2006 kidney allocation scheme identifies three levels of antigen (HLA) match, and prioritises the highest match. However, within a waiting list of 7,000, there are likely to be a number of patients who have a perfect HLA match with the donor, and 25% of transplants are carried out at perfect match levels (Research Scientist 4). Therefore the scheme features a number of other filters for deciding who should receive a kidney. Surgeon 1 explains the rationale:

 ‘Because there are 6,500 or 7000 people on the waiting list, so at every level [of match] you are going to almost have competition, for want of a better term, so even for a full house match it may well be that there are four or five people for the full house match… one of the most important things is the hierarchy of matching as your prime indicator, so that’s the utilitarian thing of the best match being likely to be the best longevity of the organ, that’s the prime thing. But then once you have that if there are points systems to then decide where the kidney goes, that allows you to perhaps allow better equity across the UK.’

A process based purely on utilitarian HLA matching does not achieve distributional equity through the random distribution of the population. Factors such as ethnicity play a large part in matching, and even with a number of finessing points within the matching equations themselves (equating unusual tissue types with close match standard ones) matching needs to be mitigated by other factors. There is, according to Surgeon 1, enough flexibility within the tissue matching to allow other factors to improve upon equitable distribution, although utility remains ‘*the prime thing*’. Therefore the score also includes: waiting time; HLA match and age combined; donor-recipient age difference; location of patient relative to donor; two technical factors relating to HLA matching; and blood group match. Changes made in 2006 emphasised waiting time at the expense of HLA matching, resulting in a higher likelihood of matching for ethnic minorities and increased equity of transplantation.[[3]](#endnote-3)

The inclusion of waiting time is important because it appeals to a natural (or least national!) sense of distributional fairness: the queue (Consultant 3). Waiting time is therefore positioned as the first factor in the list and yet, in practice the second factor is the crucial one (Research Scientist 4). Waiting time is measured in points, with patients gaining one point for every day they spend on the list; a wait of three years equates to 1095 points. The second factor combines HLA match and age: a perfectly matched patient under the age of 30 receives 3,500 points; equivalent to a ten-year stay in hospital; a relatively well matched patient under the age of 30 receives 2,000 points; a perfectly matched eighty-year-old man receives just 500 points. The exact point distributions and formulae are shown in Figure 1. The weighting of this calculation means that subsequent levels of the points system become little more than tie-breakers, although location may also play an important role with patients receiving 900 points if they are at the same centre as a donor.

Figure 1: Points scoring for kidney allocation [[4]](#endnote-4)

The shape of these curves is determined through initiative process of statistical modelling and discussion by the steering group (Research Scientist 3). Some factors, such as the weighting towards transplants in the same centre may be for what Surgeon 1 described as ‘legitimate scientific’ reasons, such as the reduction of ‘cold ischaemic time’ (i.e. the time that organs are out of a body). At the same time, it may be possible to discern some traces of previous systems, which gave priority to locality, fossilised in the points systems. The reasoning behind points systems may be fundamentally pragmatic, too:

‘[If you had a young kidney] your instinct says he would want to give that to a young person…We know that the older kidneys are not going to…last for so long.’ (Surgeon 2)

In this comment we can distinguish both a medical pragmatism and a concern for individual patient coexisting, perhaps, with the rational utility of the points system. And despite the stated intention to increase equity of access, it does appear that the points system emphasises certain goods, such as youth. Surgeon 1 describes the prioritisation of young transplant patients thus:

‘Let’s say you’re 18, the average lifespan of a kidney means that it is likely that you will need more than one kidney transplant. If we put a poorly matched kidney into you when you’re 18, then you will have antibody levels in the future, and so therefore it’s going to be harder to give you a second kidney later on down the line. So more or less, the better match should be for the younger patient. Completely different from the patient who is aged 60. The patient who is aged 60 hates being on dialysis, on the main, and would really like to have their life back, and accepts that if they get a poorly matched kidney it may not last them for a huge amount of time, but it may last until their death, from other causes. So therefore you can afford to get away with a poorer match in the more elderly patient. So…the match points count much more when you are young, but drop-off and count much less when you are old.’

The sharply decreasing curves of the points system prioritise younger patients over older patients, even at a relatively low level of matching (Research Scientist 4). The implication here is that first principles, be they queuing or distributional equity are upheld so long as they do not clash with other objectives that may be legitimately described as ‘scientific’: the avoidance of sensitisation in subsequent transplants, or the reduction of cold ischaemic time. Longer-term strategic decisions, such as the need to remove an accumulation of difficult-to-match patients from the waiting list, were also incorporated into the points system. On the other hand, despite the appeal to scientific reasoning, the intentions of the surgeons do not seem so different from the themes articulated by the non-medical public: the notion of a ‘fair innings’, where a young patient is prioritised for the sake of fairness in life lived, and an older patient should be prepared to accept a compromise ([Wilmot and Ratcliffe 2002](#_ENREF_39); [Tong, Howard et al. 2010](#_ENREF_34)). In these accounts professional care and utility are not mutually exclusive, but are expressed in different ways. In fact, it is the work of the allocation system to reframe how practitioners understand the duty of care, as becomes apparent in the following discussion.

The kidney allocation system, while the first of its kind, has met with criticism from specialists in other disciplines. Consultant 1 and Consultant 3 suggested that the Kidney Advisory Group had not adequately established its objectives before beginning its research. The decision to prioritise young people appears arbitrary to some; the transplant community recognises a systematic problem in teenagers refusing to take immunosuppressive medication which makes them overweight and spotty, consequently suffering graft failure and returning to dialysis (Nurse 1; Consultant 3). They also criticise the kidney allocation system for covering only the distribution of the organs, and not access to the waiting list. On the other hand, restricting access to the waiting list is a form of rationing and would require an additional process of screening, which may not be popular:

‘So you could say, well we’ll have an age limit, or will devise *yet another* [emphasis] scoring system and have points , and if you don’t get the required number of points for whatever reason be it a bit of age, be it a bit of comorbidity, or we just don’t like the look of your face.’ (Surgeon 2)

The consultants and scientists who worked on the kidney program deserve credit for being the pioneers of the points-based allocation system that is now being introduced into other specialties, such as pancreas transplantation. It also seems to make life easier for the surgeons. Instead of a moral choice and responsibility that might place a genuinely unacceptable burden upon physicians – the ability to dispense life and death, to arbitrate between the persistence of suffering and providing treatment, they have recourse to a system that can be justified as scientific and egalitarian. The responsibility of the surgeon recedes to a (weighty enough) technical role with no further accountability:

‘Once [patients are] on the list, it is equitable…It’s an agreed system which to a whole group of people involved in doing it seemed fairest way of allocating… It actually makes it a lot easier for us to say the machine does it [determines the allocation]. And then nobody can actually come back to you and say ‘Why did you give it to that one and not that one’. (Surgeon 2)

The points system draws our attention to the relationship between the epistemic – what we know – and practices of valuation. In the case of kidney allocation, the whole architecture of tissue matching is based on a process of tissue typing run from a small number of dedicated national laboratories. Within these laboratories three generations of tissue and DNA testing technology and the technological expertise of the laboratory technicians combine to produce a simple three digit code for every patient, donor or recipient (Research Scientist 1). This code drives the matching engine. The statistician’s model, once agreed, is converted into a software engine that runs the allocation calculations. Matching points are co-dependent between donor and recipient, and therefore the matching run must take place for every new donor, producing a score for every recipient in on the waiting list. Final scores are derived by a simple process of adding up the underlying points, giving a clear and transparent system, published online for the public to see. What is presented to the nurses operating the central duty room is a single list of potential donors, ranked by their score, whose coordinating nurses need to be contacted so that offers can be made. The concentrated work that has gone on in establishing the shape of various distributive curves within the points system is hidden from sight, part of the nest of calculations that make scientific work possible ([Latour 1999](#_ENREF_17)).

The points system is also productive of values: normative categories, such as equity and transparency, cease to be static and are enacted in the calculation of matching lists. The ‘ends’ desired by steering groups are folded into the ‘means’ of algorithms, the technology itself becoming a manner of moral exploration and translation ([Latour 2002](#_ENREF_18)). Notions of care and clinical good practice are subsumed and transformed by kidney allocation protocols; they in turn diffuse through and subvert the scientific rigidity of the protocols. The liver allocation experiment, on the other hand, tolerates no such impurity.

**# A thought experiment in allocation: livers**

‘Some people have a great deal of difficulty in seeing that what we’re trying to do here is a thought experiment, which doesn’t necessarily mean anything will change.’ (Consultant 1)

At the current time, the transplant community is in the process of developing a new universal liver transplant allocation scheme to replace the existing region by region allocation. Liver allocation is particularly difficult as patients who do not receive a transplant will certainly die, while choice of recipient is less constrained by technical issues as the only important factors are blood group and a rough match in size between donor and recipient. Livers are therefore allocated on the existing centre by centre method on the basis of clinical need. (There is also a super urgent category where patients suffering from acute liver failure, i.e. who are likely to die within a few days will receive any suitable liver that becomes available nationally). In response to a perceived need for transparency and clinical rigour ([Neuberger and Thorburn 2005](#_ENREF_23)) the transplantation community is considering moving to a quantitative score, ‘based entirely on objective measures’ (ibid. p.586). Consultant 1, who is active on the liver advisory group, described the current situation:

‘The surgeons and the physicians together decide to whom [a liver] should go. Well currently, we have about 60 patients on the transplant list, and then you can take the 60 patients and divide them up by blood group by size, but even then you still come down to: ‘Here is a donor, and I now have 14 or 15 people left who am I going to do?’ And the surgeon and physician decide, we’re going to do it in Smith or Jones. That is opaque... I can give you evidence to show that it currently is done to some degree on need, but the definition of need can be different in different centres... how you define need in Edinburgh may be different to how you define it in Cambridge.’

Among the liver community, objectivity and transparency are considered as important as justice and fairness in the maintenance of public trust, and thereby of donation levels ([Neuberger, Adams et al. 1998](#_ENREF_22)). In June 2009 the liver advisory group agreed to develop a new, national scheme, based entirely on clinical evidence. At the heart of the new scheme is the agreement that worthiness of recipients – potentially defined in many different ways – should be understood in terms of *outcomes*. It abolishes centre-based organisation in favour of a national allocation protocol that treats donated livers as a national resource and aims to maximise the national benefit, calculated on the basis of the *total years of life saved at a population level*. Consultant 1 explains:

‘Very few people have looked at the whole process of allocating health resources, not on the basis of an individual’s need or an individual’s utility but on the basis of the population life years. And that we think, because transplantation is a public good, is the way we should judge transplantation. Not on the basis of how it helps an individual but how it helps the whole population. So what you do is you add up the number of life years of all the people who died before they had a transplant, all the people who had a transplant and then died, and all the people who had a transplant and are still alive then you come to the total population life years, and you see which allocation process maximises everybody’s life years.’

As is the case with the introduction of the kidney and pancreas allocation protocols, the liver scheme focuses on delivering empirically-grounded scoring systems that can then be used in the allocation process. The advisory group has developed ‘UKELD’ (United Kingdom end-stage liver disease score), an enhanced version of the USA’s MELD ([Wiesner, Edwards et al. 2003](#_ENREF_37)), which gives an indication of the seriousness of the patient’s liver disease. UKELD has already been implemented by the steering group as a means of screening entry to the transplant waiting list and of determining urgent treatment. The Northern Liver Alliance (comprising Scotland and Northern England) has suggested a MELD score of 25 as a priority band necessitating more immediate treatment. MELD and UKELD offer points of comparison for simulation exercises and the advisory group is therefore conducting a ‘thought experiment’ on allocation policy. The experiment will test three differing allocation schemes (Research Scientist 5), following a model set out in Schaubel et al. ([2009](#_ENREF_30)): a need-based scheme; a survival-based, or best outcome, scheme; and a ‘transplant benefit’ scheme representing the net gain per patient, or estimated survival with a transplant, less estimated survival on the waiting list. The factors that underlie these models are both clinical (e.g. bilirubin and sodium in the bloodstream) and nonclinical (e.g. age, body mass index and ethnicity). The absence of tissue matching means that the scores are not co-dependent with the donor, unlike the case for kidney transplants. At the time of interview, Research Scientist 5 was in the process of running a simulation using data collected by the transplant service from August 2010 to January 2011. The experiment set out to calculate the population life years that are saved by each allocation scheme.

Consultant 1 suggested that the use of population life years represents an ‘innovative and useful’ way of assessing the value of medical interventions. Figure 2 illustrates the point. Basing allocation on survival measures alone sees mortality shifted pre- or post-transplant: a best outcome approach, offering organs to the healthiest and youngest candidates on the list produces huge gains in post-operative survival, but results in high waiting list mortality; a needs-based, or sickest-first, approach improves waiting list mortality at the cost of lower port-operative survival. As the first graph shows, it is difficult to compare the regimes. The population life years approach, on the other hand, visualises total life expectancy on both sides of the operation, across the whole patient group. An allocation regime can then be chosen on the basis of the greatest contribution to population life expectancy.

Figure 2: Liver valuations

The top graph shows the problems associated with survival measures in determining allocative regimes: mortality rates shift pre/post-transplant and resist comparison. The population life years approach, shown below, renders transplant benefits immediately commensurable.

Life years post-transplant

Life years pre-transplant

Clinical measurement schemes

Population Life Years

Pre-transplant mortality: need-based allocation

Pre- transplant mortality: best outcome allocation

0

100%

Time

Post-transplant survival: best outcome allocation

Post-transplant survival: need-based allocation

The introduction of survival measures as the most appropriate means of determining allocation, and the use of calculative regimes driven by clinical scoring methods, offers another way of articulating values. Where kidney reforms have centred on the pursuit of transparency and equity, thereby reframing clinical practice, the liver experiment understands transparency in terms of the objective rigour of clinical evidence. Population life years are perhaps the inevitable conclusion of the initial recognition that transplant organs are a public resource, with clinicians putting aside all factors beyond population benefits. Once again, through measures of transplant utility, notions of good clinical practice, of care, of equity and transparency itself, are radically transformed.

**# Ghosts in the machine: compassion and complexity**

The new allocative regimes attempt to simplify and close down the complexities of organ allocation, leaving in place a single, transparent and objective calculative framework. Yet interviews suggested that the closure is only partial, with ghosts of personal relationships and other professional values such as compassion haunting the allocation process. A social worker might, for example, object to the clinical decision to list a patient or conduct a transplant on the grounds that the patient lacks adequate social support mechanisms. Carers build personal relationships with their patients, and develop a sense of local obligation and ownership that resists the national distribution of organs and transplantation:

‘You can’t help but believe that it’s wrong. I can see from a utilitarian point of view that it’s possibly right, but you’re sitting there….[we] have a donor in [our region], and we will get Joe transplanted, because poor Joe has really struggled, and then an organisation remote says, actually big brother says that this liver goes to somebody else. Okay, that’s great for somebody else, they may be sicker, they may require it. But you’re not ours…’ (Nurse 2)

Point scores and algorithms render such considerations exogenous, irrelevant to a clinical decision, and the implementation of a national ranking system reconfigures the meaning of good clinical work. While the nurse cherishes personal relationships with her patients, a commitment to the methodology of scoring includes the recognition that the organ may make a similar or greater difference to someone else (Surgeon 2). Personal attachment to patients becomes problematic, and a hindrance to the pursuit of transparent, just outcomes. But it remains difficult for carers to relinquish all control. Standardisation has meant giving up the possibility of helping individual patients who are struggling with medication or dialysis where under the previous, local system surgeons could use their discretion to help such people. Similarly, the category of ‘compassionate listing’, where centres would send out faxes to ask for help in locating an organ for a particular patient, usually a child, has disappeared.

Perhaps, then, it is no surprise that practitioners talk of how the new systems might be manipulated. For example, given predetermined scores to access a waiting list, or to qualify for a ‘top band’ transplant, physicians could – hypothetically – manipulate the bodies of their patients to qualify for a higher score: an infection or a change in diuretic might be enough to lift a MELD score to a qualifying level.

‘All of these are entirely illegal and not looked upon in the profession as kosher, but nonetheless… it probably goes on to a certain extent, although to be fair nobody does it deliberately, because the patients themselves are precarious.’ (Nurse 2)

Under the revised allocative regime, caring for patients means surrendering them to the centralized process, not bending rules and risking patient health to nudge individuals up the score chart. Interviewees considered it unlikely that anyone would be so reckless as to act in this way; ‘gaming’ the system like this seems to exist only as an idea, a shadow of resistance to the totalizing algorithms.

Interviewees also speculated about surgeons exercising their sole remaining area of discretion to procure organs for patients who are in need and not favoured by allocation protocols. Surgeons are allowed to refuse an organ. When the central duty room offers, surgeons are expected to assess the health of the potential recipient and his or her suitability for transplant, and accept the organ only if the patient is well enough for surgery. Yet patients are out of the hospital and it may not be easy to make such an assessment; the surgeon may accept the kidney in good faith only to find that the patient is too ill to receive a transplant. In this case, the surgeon must notify the duty room and another recipient will be found, but if the kidney has already set out on its journey it will still be delivered, and can be allocated at the surgeon’s discretion. Once again, evaluations based on central allocation read that story differently: discretionary allocation to a fall-back patient has become a moment of subversion, of resistance to the algorithmic process. A pragmatic, professional judgement on the ability of a patient to undergo a transplant has been reclassified as another way of outsmarting the system, something worthy of comment:

 ‘When you look at the national figures there are certainly some units where there are an awful lot of kidneys that do not end up in the person they were first offered for.’ (Surgeon 2)

These speculations are, perhaps, only that. They are the result of colliding worlds of value, the conflicting regimes of critical care and organ supply, of national equity and personal care, of centralization and systematization versus expertise. As allocation regimes struggle for closure, placing clinical objectivity at the centre of allocation regimes, so values that previously stood as central to clinical practice may become increasingly marginalized. Nevertheless, clinical judgement and personal compassion remain evident within the transplant community, and closure remains precarious and incomplete.

**#Discussion: the moral economy of transplantation**

Contests over value encircle the practice of transplantation. In the literature, we find appeals to autonomy, ownership, justice and equity; to the desert of recipients; to scientific rationality and effectiveness. These disparate arguments are united by the notion that value is stable and separate from clinical practice, and that it can therefore be used as an organising framework for transplantation. In this chapter I have set out to demonstrate that values and practice exist in a complex relationship; as normative discourses feed into the organisation of allocation protocols, so the protocols reconfigure the meaning of those norms. In the centre of this web of value sits the organ itself, understood in terms of its compatibility with recipients, or its potential contribution towards population health. The real value of an organ arises through its use in the body of another – the longer, better life that it can offer the recipient – and so becomes apparent in relation to the embodied characteristics of those who might receive it. Compatibility and survival benefit structure the whole practice of transplantation and yet are invisible without database work and algorithmic sorting. The whole architecture of transplantation depends upon an epistemology that is entirely relative, made concrete by allocation mechanisms.

I have explored the unfolding moral economies of organ transplantation by identifying the changing practices for allocation of transplant organs since the 1990s. Several key themes emerge as practitioners struggle to synthesise moral claims and clinical considerations: a national resource, equity and most of all, utility. Redefining organs as a national resource changed the way that allocation is understood in the community, forcing clinicians to abandon local discretionary allocation in favour of more systematic and transparent approaches. The transplant community tends to classify approaches as either utility, need, or equity-based, or a ‘fudge’ or ‘hodgepodge’ of the three, but utilitarian approaches run much deeper in the community than the comments of practitioners might suggest.

Utility is the organising principle that dominates the kidney allocation scheme, through the choice of HLA matching as the key measure, and through factors such as location or age. The reduction of cold ischaemic time, a key measure in improving transplant success, is a utilitarian measure; deserving individuals may miss out, but outcomes across the population are improved. Waiting time, a proxy for equity, is given prominence in descriptions of the scheme, but appears to in practice have a light weighting in terms of points awarded. In the case of the liver group’s thought experiment, all three scores (need, utility and transplant benefit) are rendered into population life years, itself a utilitarian measure. Population life years are a vision of general utility, directing the organ where it will contribute most. The population life year calculation is a classic utilitarian approach, directing resources to maximise aggregate benefits, irrespective of its effects on individuals ([Ryan 1987](#_ENREF_29)). Indeed, the criticism levelled by one nurse is that doctors, when assessing whether to accept individuals onto the waiting list, are simply too ‘clinical’, ignoring personal circumstances that might make transplantation profoundly inappropriate.

This criticism – that clinicians are over-clinical – opens up a discussion of the role of professional care and judgement in a practice organised by allocation protocols. We can see that the understanding of care has been radically reconfigured by the implementation of algorithms. From the predicate that organs are a national resource, we arrive soon enough at the allocation by survival benefit proposed under the liver thought experiment. With transplantation framed in this way, the good clinician is committed to the needs of the population, rather than individual patients. The organ, with the potential to do good anywhere, must be directed where it can do the most good, and that is achieved by a rigorous compliance to the evaluatory framework demanded by the algorithm. Good practice becomes good measurement, reporting, and a dispassionate handling of patients in one’s immediate care. Yet the process of closure is far from complete, and ghosts of older, more subjective realms of valuation – compassion, personal attachment and strategic gaming – can be glimpsed in the narratives of practitioners.

This chapter highlights the materially and technically embedded nature of value in the transplant community. The debates on valuation, political objectives and clinical practice that take place as steering groups discuss allocation protocols have been finalised and shut into the ‘black boxes’ of allocation protocols. From there, they shape the world as their designers intended. Allocation algorithms are ‘performative’ ([MacKenzie 2006](#_ENREF_20)): there has been a striking similarity between the predicted distribution of transplants and the outcome of the system during its first few years of operation (Research Scientist 4). The algorithms also bring about a more general change in the way that practice should be done: specifying how to calculate means redefining what counts, what matters. New ways of calculating and visualising illness give rise to new understandings and principles for action ([Mol 1999](#_ENREF_21)): knowing *what counts* is a vital step in deciding how to act.

In a similar way, scores and rankings act as cognitive framings that organize the decisions of participants, and shape the world accordingly. Scores for liver health make visible a granular ranking of sickness, and a likelihood of mortality that can be manipulated and parsed by medical scientists. Categories of illness, such as the Northern Liver Alliance’s priority band, expose patients to a further politics ([Bowker and Leigh Starr 1999](#_ENREF_5)) of rationing and need. Valuing, in the case of transplantation, is inseparable from knowing: value depends upon the epistemic – what is known and what is worth knowing. How participants come to understand and make sense of what counts – in a very particular context – has been the subject of this chapter.

Finally, as this chapter has demonstrated, the stabilization of value can only ever be partial and temporary. The push to clinical objectivity leads practitioners to assert the other values, such as compassion and individual expertise that they have accumulated over many years of medical work – ‘all that matters to [the patients] is that we know that they are sick’ (Nurse 2). Frames of valuation persistently overflow and must once again be reframed ([Callon 1998](#_ENREF_7)). The moral economy of transplantation, as this chapter has shown, is unsettled, fluid and elusive. It remains a work in progress, and will remain an important site for studies of medical ethics and organisational values for many years.

**#References**

Ahrens, Thomas and Christopher S. Chapman (2006). "Doing Qualitative Field Research in Management Accounting: Positioning Data to Contribute to Theory." *Accounting, Organizations and Society* **31**(8): 819-841.

Anteby, Michel (2010). "Markets, Morals, and Practices of Trade: Jurisdictional Disputes in the U.S. Commerce in Cadavers." *Administrative Science Quarterly* **55**(4): 606-638.

Boeije, Hennie (2002). "A Purposeful Approach to the Constant Comparative Method in the Analysis of Qualitative Interviews." *Quality & Quantity* **36**(4): 391-409.

Boltanski, Luc and Laurent Thevenot (2006). *On Justification*. Princeton, Princeton University Press.

Bowker, Geoffrey C and Susan Leigh Starr (1999). *Sorting Things Out*. Cambridge, Massachusetts, MIT Press.

Brown, Nik, Laura Machin and Danae McLeod (2011). "Immunitary Bioeconomy: The Economisation of Life in the International Cord Blood Market." *Social Science &amp; Medicine* **72**(7): 1115-1122.

Callon, Michel (1998). *The Laws of the Markets*. Oxford, Oxford University Press.

Cherry, Mark J. (2005). *Kidney for Sale by Owner*. Washington DC, Georgetown University Press.

Childress, James F. (1989). "Ethical Criteria for Procuring and Distributing Organs for Transplantation." *Journal of Health Politics Policy and Law* **14**(1): 87-113.

Daston, Lorraine (1995). "The Moral Economy of Science." *Osiris* **10**(ArticleType: research-article / Issue Title: Constructing Knowledge in the History of Science / Full publication date: 1995 / Copyright © 1995 The University of Chicago Press): 2-24.

Dussauge, Isabelle, et al. (2014). Value Practices in the Life Sciences: What Might It Mean to Study the Enactment of Values in the Life Sciences? *Value Practices in the Life Sciences*. I. Dussauge, C.-F. Helgesson and F. Lee. Oxford, Oxford University Press.

Forsythe, John (2009). *Transplantation: A Companion to Specialist Surgical Practice*. London, Saunders.

Freeman, R. B. (2007). "Survival Benefit: Quality Versus Quantity and Trade-Offs in Developing New Renal Allocation Systems." *American Journal of Transplantation* **7**(5): 1043-1046.

Johri, M and PA Ubel (2003). "Setting Organ Allocation Priorities: Should We Care What the Public Cares About?" *Liver Transplantation* **9**(8): 878-880.

Latour, Bruno (1987). *Science in Action: How to Follow Scientists and Engineers through Society*. Cambridge MA, Harvard University Press.

Latour, Bruno (1999). *Pandora's Hope*. Cambridge, Massachusetts, Harvard University Press.

Latour, Bruno (2002). "Morality and Technology: The End of the Means." *Theory, Culture and Society* **19**(5/6): 247-260.

Latour, Bruno (2007). *Reassembling the Social: An Introduction to Actor-Network-Theory (New Edition)*, Oxford University Press.

MacKenzie, Donald (2006). *An Engine, Not a Camera: How Financial Models Shape Markets*. Cambridge, MIT Press.

Mol, Annemarie (1999). Ontological Politics. A Word and Some Questions. *Actor Network Theory and After*. J. Law and J. Hassard. Blackwell Publishers, Oxford**:** 74-89.

Neuberger, James, et al. (1998). *Assessing Priorities for Allocation of Donor Liver Grafts: Survey of Public and Clinicians*.

Neuberger, James and Douglas Thorburn (2005). "Meld - Moving Steadily Towards Equality, Equity, and Fairness." *Liver Transplantation* **11**(5): 585-587.

Oniscu, Gabriel C, et al. (2003). "Equity of Access to Renal Transplant Waiting List and Renal Transplantation in Scotland: Cohort Study." *BMJ* **327**(7426): 1261.

Persad, Govind, Alan Wertheimer and Ezekiel J. Emanuel (2009). "Principles for Allocation of Scarce Medical Interventions." *The Lancet* **373**(9661): 423-431.

Reinecke, Juliane (2010). "Beyond a Subjective Theory of Value and Towards a ‘Fair Price’: An Organizational Perspective on Fairtrade Minimum Price Setting." *Organization* **17**(5): 563-581.

Roth, Alvin E. (2007). "Repugnance as a Constraint on Markets." *Journal of Economic Perspectives* **21**(3): 37-58.

Roth, Alvin E., Tayfun Sönmez and M. Utku Ünver (2005). "A Kidney Exchange Clearing House in New England." *American Economic Review* **95**(2): 376-380.

Ryan, Alan (1987). Introduction. *John Stuart Mill and Jeremy Bentham: Utilitarianism and Other Essays*. A. Ryan.

Schaubel, Douglas , et al. (2009). "Survival Benefit-Based Deceased-Donor Liver Allocation." *American Journal of Transplantation* **9**(4.2): 970-981.

Shapiro, R. (2007). "Kidney Allocation and the Perception of Fairness." *American Journal of Transplantation* **7**(5): 1041-1042.

Sharp, Lesley A (2006). *Strange Harvest*. Berkeley, University of California Press.

Taylor, James (2005). *Stakes and Kidneys*. Aldershot, Hants, Ashgate Publishing Company.

Tong, Alison, et al. (2010). "Community Preferences for the Allocation of Solid Organs for Transplantation: A Systematic Review." *Transplantation* **89**(7): 796-805.

Ubel, Peter and George Loewenstein (1996). "Distributing Scarce Livers: The Moral Reasoning of the General Public." *Social Science and Medicine* **42**(1049-1055).

Weir, Robert (1995). "The Issue of Fairness in the Allocation of Organs." *Journal of Corporate Law* **20**: 91-108.

Wiesner, Russell, et al. (2003). "Model for End-Stage Liver Disease (Meld) and Allocation of Donor Livers." *Gastroenterology* **124**(1): 91-96.

Wilkinson, Steven (2003). *Bodies for Sale : Ethics and Exploitation in the Human Body Trade*. New York, Routledge.

Wilmot, Stephen and Julie Ratcliffe (2002). "Principles of Distributive Justice Used by Members of the General Public in the Allocation of Donor Liver Grafts for Transplantation: A Qualitative Study." *Health Expectations* **5**(3): 199-209.

1. The chapter is based on empirical work conducted in the first half of 2011. Primary sources have been interview material collected in 12 interviews with members of the transplant community: three consultants (i.e. specialist doctors but not surgeons), two transplant surgeons, five research scientists involved in various aspects of the allocation process, and two nurses involved in retrieval and allocation of organs. Interviewees are detailed in Table 1. With one exception interviews were conducted in person; I was also able to visit a laboratory and a research seminar. Additional data on allocation come from the large quantity of publicly available records. The National Health Service publishes its allocation policies, and the advisory committees publish minutes of the quarterly meetings. The research scientists also made available to me detailed documentation of allocation protocols and material from presentations made to private health service committees. The data have been analysed through a process of comparison (Boeje 2002) to produce a plausible (Ahrens and Chapman 2006) narrative account of the development of current standards.

Table 1: Interviewees

|  |  |  |  |
| --- | --- | --- | --- |
| Reference | Role summary | Interview length  | Recorded by |
| Consultant 1 | Medical specialist | 45 mins | Telephone interview, taped |
| Consultant 2 | Intensive care doctor | 1 hour | Tape |
| Consultant 3 | Medical specialist | 30 minutes | Notes  |
| Nurse 1 | Transplant coordinator | 2 hours | Tape |
| Nurse 2 | Transplant coordinator | 1 hour 15 | Tape |
| Research scientist 4 | Analyst | 30 minutes | Notes |
| Research scientist 1 | Laboratory manager | 2 hours | Tape, notes, laboratory visit |
| Research scientist 2 | Academic | 1.5 hours | Tape, notes, seminar attendance |
| Research scientist 3 | Analyst | 1 hour | Notes and presentation materials |
| Research scientist 5 | Analyst | 1 hour | Notes and presentation materials |
| Surgeon 1 | Transplant surgeon | 1 hour | Tape |
| Surgeon 2 | Transplant surgeon | 1 hour | Tape |

 [↑](#endnote-ref-1)
2. Organ retrieval is always carried out under general anaesthetic: reasons for this appear to be largely technical, although the possibilities are discussed by Sharp Sharp, Lesley A (2006). *Strange Harvest*. Berkeley, University of California Press. [↑](#endnote-ref-2)
3. NHSBT Transplant Activity Report 2009/2010, p.21. [↑](#endnote-ref-3)
4. The exact formula is: 3500/(1+ (age/55)5) for level I mismatch patients; 2000/(1+ (age/55)5) for level II mismatch patients; 500/(1+ (age/55)5) for level III mismatch patients.

Graph is drawn from formulae. [Source: http://www.organdonation.nhs.uk/ukt/about\_transplants/organ\_allocation/kidney\_%28renal%29/renal\_organ\_sharing\_principles/kidney\_organ\_allocation\_scheme\_2006.asp

Accessed 28.11.2012] [↑](#endnote-ref-4)