

# Teenager and the transplant: how the case of William Verden highlights action is needed to optimise equitable access to organs for patients with impaired decision-making

Bonnie Venter,<sup>1</sup> Alexander Ruck Keene,<sup>2,3</sup> Antonia J Cronin<sup>4,5</sup>

<sup>1</sup>Centre for Health, Law, and Society, University of Bristol, Bristol, UK

<sup>2</sup>39 Essex Chambers, London, UK

<sup>3</sup>Dickson Poon School of Law, King's College London, London, UK

<sup>4</sup>Transplant Renal and Urology Directorate, Guy's and St Thomas' Hospitals NHS Trust, London, UK

<sup>5</sup>Centre for Nephrology, Urology and Transplantation, King's College London, London, UK

## Correspondence to

Bonnie Venter, Centre for Health, Law, and Society, University of Bristol, Bristol BS8 1HH, UK; [bonnie.venter@bristol.ac.uk](mailto:bonnie.venter@bristol.ac.uk)

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## ABSTRACT

In February 2022, the Court of Protection was faced with the question of whether a kidney transplant was in the best interests of William Verden. The case highlighted the legal, ethical and clinical complexities of treating potential kidney transplant patients with impaired decision-making. Above all, it exposed the potential risk of discrimination on the basis of disability when treatment decisions in relation to potential kidney recipients with impaired capacity are being made. In this paper, we draw on the Verden case to (1) examine the role of the Court of Protection in cases relating to patients with impaired decision-making capacity who require a transplant, (2) to highlight the lack of empirical data on patients who have faced inequitable access to transplant and (3) highlight the shortcomings of the existing legal and regulatory framework in England and Wales guiding clinical decision making for patients in William's position. We consequently argue that there is a clear need for action to ensure equitable access to transplant for those in William's position. Furthermore, we suggest that there is a responsibility incumbent on policy makers and clinicians alike to develop a meaningful, and meaningfully operational, framework centred on preventing discrimination against potential organ recipients based on their decision-making capacity.

## INTRODUCTION

The case of William Verden, heard before the Court of Protection in February 2022,<sup>1</sup> shone a rare public spotlight on the situation of patients with impaired decision-making capacity requiring kidney transplants. In this paper, we examine what the case tells us about the role—and limits—of the Court of Protection in decision making for those in William's position, not least so to ensure that the impression is not given that it is possible to have recourse to have the court to secure access to kidneys (or indeed other organs) that are not otherwise available. We then go on to examine the wider implications of the case and, in particular, to highlight the potential that the current framework does not do enough to optimise equitable access to kidney transplants in patients with impaired decision making. The shortcomings of the current framework, therefore, underscores the importance of policy makers and clinicians alike to develop guidance centred on preventing discrimination against potential organ recipients based on their decision-making capacity.

## THE VERDEN CASE: BEST INTERESTS DECISION(S) AND A KIDNEY TRANSPLANT

In February 2022, the Court of Protection was faced with the question of whether a kidney transplant was in the best interests of William Verden. William, 17<sup>i</sup> at the time of the case, was diagnosed with a rare kidney condition (steroid-resistant nephrotic syndrome) in December 2019.<sup>2</sup> William also had diagnoses of moderate to severe learning disabilities with autistic spectrum condition, attention deficit hyperactivity disorder and accompanying behavioural disturbances (such as tampering with dressings that protect lines or tubes inserted into his body from which he was attached to the dialysis machine). From April 2020 to September 2021, peritoneal dialysis was undertaken but was unsuccessful. Haemodialysis (HD) was commenced but proved to be challenging as there were various incidents where the vascular access lines were 'disturbed' due to William's (supposed) tendency to scratch the dressings of his access site. Because of difficulties experienced with the provision of HD, the question of whether a kidney transplant would be in William's best interests came into focus.

All parties agreed that William's cognitive impairments meant that he could not make a decision regarding his medical treatment. The clinical team and his mother could not agree as to whether a transplant was in his best interests, and the matter, therefore, came before the Court of Protection. This was the first time that such an application had come before the court (at least in any case giving rise to a reported judgement).

Initially, the treating team at Manchester University National Health Service (NHS) Foundation Trust sought a declaration that it was not in William's best interests to undergo a kidney transplant. The

<sup>i</sup>We note that, given William's age<sup>1</sup> and inability to make the relevant decisions, it would potentially have been open to the clinical team consider matters through the prism of parental responsibility. However, the Mental Capacity Act 2005 provides a parallel structure for making treatment decisions in relation to minors aged 16/17 with impaired decision-making capacity. As the Mental Capacity Act 2005 was the framework used by the clinicians (explaining why they approached the Court of Protection, rather than the Family Division of the High Court), we limit our discussion to the 2005 Act. We note, though, that even if the High Court was approaching matters in relation to a child by reference either to the Children Act 1989 or under its inherent jurisdiction, it could not 'magic up' an organ if one was not available: see, by analogy, *Holmes-Moorhouse v Richmond-upon-Thames LBC* (2009) UKHL.



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Trust's position was based on the fact that they were of the opinion that continuing HD until it was no longer possible was less harmful than subjecting William to the harms associated with the transplant and postoperative treatment. The Official Solicitor (representing William) and his mother, Amy McLennan took the position that it was in William's best interests to have a transplant. It soon became clear that the best interests decision was more nuanced than initially suggested, encompassing more than just a consideration of whether a transplant in itself was in William's best interests.

It was apparent from the medical evidence presented in the case that William's treatment plan involved complex medical decision making. Essentially, two factors added to the complexity of this case. First, evidence suggested that there was a high likelihood (between 47% and 80% or above chance) that his steroid-resistant nephrotic syndrome would recur in the transplanted kidney. If this were to happen, William would require treatment consisting of numerous Plasma Exchange sessions over an unspecified period. Second, the treating clinicians were concerned as to how William's past behaviour of interfering with dressings and lines would be managed postoperatively, to prevent these lifesaving lines and tubes from becoming dislodged. The situation was further exacerbated by concerns over William's unpredictable behaviour and difficulty with adapting to sudden change, particularly within the paediatric intensive care unit environment. Notably, as the hearing progressed, the treating Trust's initial position that a transplant was not in William's best interests changed to one where they deferred to the court to decide what was in his best interests.

It was clear that, if William was to have the best possible chance of a successful transplant, then significant adjustments would have to be made during his postoperative care. This included a high probability of being sedated and ventilated, and as evidence suggested this treatment route carried the risk of causing psychological harm (including post intensive care syndrome), which could last for years. The Court ultimately had to consider the risks from the transplant and postoperative treatment plan and decide 'what is the least bad decision for William'. In reaching her decision, Mrs Justice Arbuthnot strived to place emphasis on what was important to William. Mrs Justice Arbuthnot stressed:

...that what matters to William is living with his family, playing sport and doing useful things such as laminating documents, and other helpful odd jobs. He has a good quality of life which he would want to continue. He says he wants a transplant, although he does not understand what that will entail. He has been accustomed since July 2021 to the idea of a transplant. William wants to live and to continue doing the things he enjoys (para 136)

Mrs Justice Arbuthnot determined that it was in William's best interests to have a kidney transplant and to be sedated and ventilated for up to 14 days after disease occurrence (if necessary) to allow for the agreed treatment plan. In August 2022, it was reported that a suitable deceased donor was found, and that William underwent a kidney transplant—at the time of writing, it appeared that there had been no signs of disease recurrence in the transplanted kidney.<sup>3</sup>

### WHY THE COURT OF PROTECTION?

As stated earlier, the Court of Protection had not previously been involved with an organ transplantation case prior to the Verden case. Issues involving donation by adults with impaired decision-making capacity have previously come

before the courts,<sup>4 5</sup> and it appears to be understood that, whether as a matter of law or good medical practice, such decisions should come to the court.<sup>6</sup> However, these cases raise different issues, not least that the decisions in question are not, directly, a matter of life or death for the subject of the proceedings.

Why, then, would the Court of Protection be involved in a case about transplantation? And what, precisely, should its role be in such a case? To answer these questions, we need to delve somewhat beneath the surface of the case.

While we understand why the case was presented to the Court of Protection as being one of whether a kidney transplant was in William's best interests, this could not, strictly, have been true. The Supreme Court has made clear that best interests decisions, whether made informally outside court, or by the court itself, can only be decisions which the person themselves can actually have made themselves, and can only be made between options actually available to the person.<sup>7</sup> At the point of the case being before the court, there was no kidney available for William: his mother had been making vigorous efforts to publicise his case in hopes of obtaining such a donor.<sup>8</sup> Strictly speaking, therefore, the court should not have allowed itself to be lured into making a hypothetical decision as to whether a transplant was in William's best interests if a kidney did become available. At most, it could have made a decision on William's behalf under s.16 (2) (a) Mental Capacity Act (MCA) 2005 to ask to be put forward for a transplant. That would have required consideration of the factors Mrs Justice Arbuthnot took into account in her analysis, but through a subtly different prism.

This might seem akin to legal dancing on the head of a pin. However, it has important consequences. The first of these is as to the circumstances under which there is an expectation that the court will be involved in relation to potential organ recipients with impaired decision-making capacity. It would be extremely unfortunate if the case were to leave clinicians—and perhaps more to the point concerned family members—with the impression that it is possible to have recourse to the court as a tool to secure access to organs which are not otherwise available. The court cannot 'magic up' such organs. Nor is it the judicial body best placed to determine whether allocation policies are lawful: that is the High Court, by way of judicial review.

It would also be unfortunate if the impression were to be gained that the court's imprimatur were routinely to be required to advance a patient with impaired decision-making capacity for registration on the national transplant waiting list. There is no such requirement, s.5 MCA 2005 providing all the legal 'cover' that might be required for the actions to be taken in the name of the person's best interests. It is only where there is a lack of agreement between those concerned with the person's welfare, or where the decision is finely balanced, that the court should be involved.<sup>9</sup>

Much more important on a day-to-day basis are the operational guidelines governing decisions about the putting forward of patients for transplant. The Human Tissue Authority's Code of Practice provides guidelines on how to approach donors who lack decision-making capacity.<sup>10</sup> However, as we develop below, there are no equivalent guidelines in relation to potential recipients, a matter we suggest of some considerable concern given the likelihood that William Verden's situation is unusual, but not unique.

## ARE THERE OTHER CASES SIMILAR TO THAT OF WILLIAM VERDEN?

Evidence from the USA suggests that historically patients who lack decision-making capacity have faced inequitable access to the transplant pathway.<sup>11</sup> The authors of this paper are in the process of collecting empirical data for the UK as no data are available. Yet, we have no reason to believe that the position is materially different from that of the USA. We should emphasise that our working hypothesis is that this is not because clinicians are consciously discriminating against those with impaired decision-making capacity; rather, it is because clinicians are not always prompted to approach the issues to which impaired decision-making capacity gives rise in a suitably structured fashion.

Transplantation presents clinicians with complex case-to-case decision making that is dependent on a range of factors. Transplant outcome measures such as medication adherence, graft outcome, patient outcome and quality-of-life are commonly used as indicators to determine transplant eligibility.<sup>12</sup> Patients who might lack decision-making capacity are often excluded based on a belief that they are at a heightened risk of poorer outcomes.<sup>12</sup> For example, it might be argued that a patient who has impaired decision-making capacity would struggle to comply with the post-transplant regimen of taking antirejection medication. However, in considering the relationship between mental capacity and transplant outcomes, Thom *et al* found that there was very limited evidence to support concerns of medical adherence, and very weak evidence of worse patient outcomes and quality of life.<sup>12</sup> This is also echoed by Chen *et al* who claim that there is not an appropriate evidence base to support the use of intellectual disability as a contraindication to receiving an organ transplant.<sup>11</sup> Concerns have also been raised that clinicians might regard a lack of decision-making capacity in and of itself as an absolute or contraindication to access transplant as opposed to identifying a medical reason to exclude the individual.<sup>13</sup>

In light of these matters, Thom *et al* have provided useful recommendations to assist clinicians and policy makers in their decision making relating to the eligibility of potential transplant who might lack decision-making capacity.<sup>12</sup> However, as we develop in the next section, we suggest that current legal and regulatory framework in the UK within which transplant decisions are made presents additional challenges for clinicians.

## LEGAL AND REGULATORY FRAMEWORK: SHORTCOMINGS

As it currently stands, access to transplant takes places within a legal and regulatory framework that is limited, and in some cases

ambiguous. The UK (unlike some US states) does not have laws that explicitly focus on preventing organ transplant discrimination.<sup>11</sup> Instead, general legal principles are rather applied to achieve antidiscriminatory practices. An overview of the guiding framework is provided in (table 1), and the rest of this discussion is focused on emphasising general points relating to the law and the shortcomings we have identified within the framework.

When considering a potential organ recipient the framework has two functions, (1) securing consent to carrying out the transplant itself, and any consequential interventions, and (where obtaining such consent is not possible) acting in the patient's best interests and (2) ensuring both that this assessment, and the decision to put the patient forward for transplant is done in a non-discriminatory manner.

If we then first consider the matter of informed consent, the main instruments that are applied are the MCA 2005, and consent policies as set out by the NHS Blood and Transplant (NHSBT),<sup>13</sup> the British Transplantation Society<sup>14</sup> and the General Medical Council.<sup>15</sup> The clinical implementation of the MCA in and of itself presents numerous challenges. By way of one example, take the application of the presumption of capacity contained in s.1 (2) MCA 2005. Misunderstanding of this presumption leads to two equally problematic outcomes. The first is where it is simply assumed that a patient lacks decision-making capacity due to, for instance, a learning disability. The second is where the presumption is misused to take what is, in fact, an 'incapacitous no' to justify decisions not to proceed.<sup>16</sup>

Consent policies are also notably lacking in detail. While they have been updated to take account of the Supreme Court's decision in Montgomery,<sup>17</sup> focusing on the information required for consent to be informed, they do not provide detailed guidance about how to proceed where the person being considered potentially to be put forward to transplant has impaired decision-making capacity. In the few instances where these documents refer to patients who lack decision-making capacity, the only guidance provided is to consult the MCA and its accompanying Code of Practice—amounting thus to limited assistance for our scenario. This means, for instance, the clinicians are not provided with guidance addressing such basic matters as to the decisions that the patient may need to take (and hence in respect of which the capacity needs to be considered), and hence what information may be relevant to those decisions. Nor are they provided with guidance as to more complex matters such as what factors to take into account when determining how robust measures taken in the name of best interests to secure post-transplant compliance can be. It is telling that in William Verden's case that

**Table 1**

Overarching Law	<ul style="list-style-type: none"> <li>▶ Mental Capacity Act 2005</li> <li>▶ Human Rights Act 1998</li> <li>▶ Equality Act 2010</li> <li>▶ Health and Social Care Act 2008</li> </ul>
Regulations	▶ Health and Social Care Act 2008 (Regulated Activities) Regulations 2014
Policy	<ul style="list-style-type: none"> <li>▶ National Health Service Blood and Transplant-Patient Selection and Organ Allocation Policy (POL200/5)</li> <li>▶ National Health Services Blood and Transplant-patient selection and organ allocation policies review and approval (organs) (POL223/3)</li> <li>▶ National Health Service Blood and Transplant-Guidelines for Consent for Solid Organ Transplants (POL191/1)</li> <li>▶ British Transplantation Society-Consent for Solid Organ Transplants Consent for Solid Organ Transplants (2015)</li> <li>▶ General Medical Council-Decision Making and Consent Decision Making and Consent (2020)</li> </ul>
International Instruments	<ul style="list-style-type: none"> <li>▶ European Convention on Human Rights</li> <li>▶ Convention on the Rights of Persons with Disabilities</li> <li>▶ WHO Resolution on Human Organ and Tissue Transplants (Resolution WHA63.22)</li> <li>▶ WHO Guiding Principles on Human Cell, Tissue and Organ Transplants</li> </ul>

no one before the court was able to point to any relevant professional guidance to enable structured decision making along the lines of that available in the context of decision making around clinically assisted nutrition and hydration.<sup>18</sup>

The second function of the framework is to ensure that patients who require a transplant are not discriminated against. This framework also seeks to ensure that reasonable adjustments are implemented when a person is placed at a substantial disadvantage due to a disability. The overarching law includes the Equality Act 2010, the Human Rights Act 1998 and (although in a more complicated form, not being a ‘domesticated’ legal instrument, the UN Convention on the Rights of Persons with Disabilities). The NHSBT Patient Selection and Organ Allocation Policy (POL200/5), consistent with guidance from the WHO’s guidance,<sup>19</sup> emphasises the need for an equitable allocation approach.

On its face, it might be thought that the combination of the provisions set out above provide a suitable protection against discrimination. But ensuring that a patient is not discriminated against in practice might prove to be more challenging. For instance, Thom *et al* emphasise that the clinical criteria for transplant should be determined independently from whether a potential recipient has the required decision-making capacity.<sup>12</sup> Here, Thom *et al* recommend that clinicians who are assessing patients with impaired decision-making capacity should assume (unless indicated otherwise) that a patient would want to be put forward for transplant.<sup>11</sup> This way a decision about a patient’s eligibility is based on a medical reason as opposed to their decision-making capacity. Practical barriers, such as the time and resources required, to assess a patient should also be taken into consideration. However, again, these matters are not considered in any of the guidance documents which are before clinicians confronted with decision making in cases such as William’s.

Finally, we note that William Verden’s case also raises the spectre of the position of patients without a champion such as William’s mother. Section 37 of the MCA 2005 provides for the instruction by NHS bodies of Independent Mental Capacity Advocates in relation to serious medical treatment decisions where the patient (over 16) is ‘unbefriended,’ but empirical data are lacking as to (1) whether and when decisions to put a patient forward for donation are regarded as falling within the scope of this provision (a matter not addressed in guidance available to clinicians) and (2) how effective IMCAs are in such situations.

We suspect that it is unlikely that the Westminster Parliament would ever pass legislation requiring equitable access to organ transplants, because—as outlined above—such an approach is at odds with the conventional approach to legislation in the UK. It may be that the Down Syndrome Act 2022 could provide a partial exception to this rule through the statutory guidance it proposes for the NHS (among other authorities) to meet the needs of persons with Down Syndrome. Concurrently, the guidance will also be a useful tool for individuals with Down syndrome and their families (or carers) to fully understand the care they can expect. Yet it is unlikely to descend to fine-grained details in respect of transplant access. We also suggest that, in any event, that real change is a product less of legislative diktat and more of operational guidance that clinicians have before them in their day-to-day practice.

In the circumstances, therefore, it is, we suggest, problematic that there is a lack of sufficient practical, ‘gritty,’ detail in the national guidance available to secure against the risk of discrimination on the basis of disability when it comes to decision making in relation to potential recipients with impaired capacity. Indeed, we might even go so far as to suggest that the relevant

bodies would be acting irrationally if they were not to produce such guidance.

## WAY FORWARD?

We are sure that all clinicians involved in this work would agree that individuals with impaired decision-making capacity are no less deserving to be put forward for transplant than those without such an impairment. However, William Verden’s case has brought to the fore the potential for a gap between this ideal and reality. As we have sketched out above, this potential is accentuated by a combination of a complex legal and regulatory landscape and ambiguous (or silent) guidance, which not only leads to the risk of inconsistency in practice, but also of discrimination. We suggest that there is a responsibility incumbent on policy makers and clinicians alike to develop a meaningful, and meaningfully operational, framework centred on preventing discrimination against potential organ recipients based on their decision-making capacity. Although, this paper serves as a springboard to invoke a debate on this urgent matter, we would like to propose at this stage that (1) the recommendations developed by Thom *et al*,<sup>11</sup> which we refer to above should act as a starting point to develop professional guidance and (2) ideally such guidance should be developed jointly and involve NHSBT as the relevant body responsible for the oversight and implementation of organ donation and allocation schemes, relevant stakeholders (eg, BTS), as well as, representation from people with cognitive impairments and the wider clinical transplant community.

**Twitter** Bonnie Venter @TheOrganOgress

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