

# Impact of COVID-19 on Organ Donation and Transplantation in the UK:

## Lessons learnt and opportunities for future

### Abstract

The COVID-19 pandemic has placed considerable strain on the allocation of healthcare resources. In this research, we explored the views of healthcare professionals in the UK on the countrywide management of organ donation and transplantation during the first COVID-19 surge in spring 2020.

**Methods:** An internet based survey was developed and distributed over a 2 week period in May/June 2020.

**Results:** Three hundred and fourteen professionals responded, covering all organ donation and transplant regions across the UK. Data suggest a considerable degree of scaling back of activity in all but one region (Northern Ireland). A range of absolute criteria for organ donation and transplantation were highlighted that have since been implemented in practice.

Notable strengths of the countrywide response included the donation and transplant community acting responsibly and proportionately (51.6%), providing access to up to date information and data (43.9%), and communicating risk (40.8%). Mixed views were expressed on equity in resource allocation with 32% aligning to inequity, 28% to equity and 17% of respondents stating that issues of equity are not relevant in a crisis.

**Conclusion:** Findings highlight that managing scarcity is complex during a pandemic. Embedding ethical values in recovery and future preparedness for threats should be a priority.

**Key words:** Transplantation; Healthcare professionals; Viewpoint; COVID-19; Mixed-methods

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## INTRODUCTION

The World Health Organisation (WHO) declared the novel coronavirus (SARS-CoV-2) a pandemic in March 2020. The UK has seen particularly high rates of transmission and death from the disease. As of 11<sup>th</sup> February 2021, there had been over 3.9 million confirmed cases and 115,529 fatalities [1]. The National Health Service (NHS) responded by reconfiguring to increase capacity for COVID-19 positive cases and to minimise further risk of transmission [2]. Inevitably, this has impacted how patients are treated for a range of other conditions [3-5]. During the first surge of COVID-19 infections in April 2020, organ donation and transplant programme activity was selectively paused or suspended. Living donor transplantation was completely stopped. Overall there was a 72% reduction in transplants from deceased donors [6]. Estimates suggest this has increased the number of people waiting for a solid organ transplant by 16% and significantly lengthened the median time to intervention [6]. As the UK progressed through its 3<sup>rd</sup> case surge, challenges continued for donation and transplant programmes. The huge effect of the pandemic on patients raises important questions about how the organ donation and transplant community has responded, and how the increased urgency and demand for transplants should be managed.

Through an online survey, we explored the views of organ donation and transplantation healthcare and administrative/management staff in the UK on the countrywide response to COVID-19. Importantly, we also considered the circumstances under which the community felt that organ donation and transplantation activity should continue, so as to map findings to practice.

## MATERIALS and METHODS

### *Survey Design*

This was an online cross-sectional study involving a survey designed to explore healthcare and administrative/management staff views on organ donation and transplantation during the first surge of the COVID-19 pandemic in the UK. The survey was developed using a Delphi methodology [8]. The authors specified the scope of the survey. They include a mix of healthcare professionals with expertise in organ

donation, organ retrieval and implantation, pre and post-transplant care of patients, and general research methodology.

Questions were devised around five key areas:

- respondent demographics and job characteristics;
- impact of COVID-19 on organ donation and transplant programmes in employing NHS Trusts;
- views on equitable access to healthcare resources during the pandemic;
- absolute conditions under which transplant activity should resume;
- and what the community has done well in response to the pandemic.

Two free text comment boxes were also included to allow respondents to elaborate on their views about equity and learning during the pandemic. Overall, there were 22 items. Prior to the online launch, the survey underwent expert review by professionals in national positions of responsibility in relation to organ donation and transplantation. This resulted in some questions being refined to make the survey fully inclusive of donor and transplant side issues.

### *Dissemination of Survey*

To facilitate a rapid response, the survey was disseminated electronically via the weekly NHS Blood and Transplant (NHSBT) Organ Donation and Transplantation Directorate (NHSBT ODT) bulletin. The survey was also distributed to the membership of the British Transplantation Society, the Renal Association, and the mailing list of the British Renal Society. The Renal Association facilitated dissemination of the survey to the Clinical Leads of all Transplanting Centres across the UK and the British Renal Society facilitated dissemination to allied professional groups, including the UK Renal Pharmacy Group. The UK National Clinical Lead for Organ Donation facilitated dissemination to all UK Clinical Leads for Organ Donation (CLODs) and Regional Leads for Specialist Nurses in Organ Donation (SNODs). Multiple networks were used so as to capture diverse views and to ensure a spread of responses across different regions. Responses were collected over a two week period in May/June 2020, with no follow-up reminders since evidence suggests that this is less effective for web-based surveys [9]. Ethical approval was granted by the University of Hertfordshire Health, Science, Engineering and

Technology Ethics Committee with Delegated Authority (LMS/SF/UH/04170).

## ANALYSES

The data were explored in descriptive terms using frequencies and percentages in SPSS (version 26). Free text comments were analysed in NVivo (version 12) and using thematic analysis as described by Braun and Clarke [10]. An inductive approach was used with coding and the development of themes driven by the semantic content of the comments. One of the authors (AH) analysed all comments using a structured approach. We segregated comments by the two free text items and analysed the data separately. Analyses then progressed to review the data more holistically in the generation of overall themes. Quality assurance involved the first author (SS) reviewing a random sample of 25% of all comments and discussing coding with AH. Discrepancies were resolved through discussion and related exclusively to the specific alignment of comments to sub-themes within the master themes.

## RESULTS

### Survey respondents

Three hundred and fourteen people accessed the survey and engaged with at least 50% of items. Of the total sample, 266 (85%) respondents completed all items. Figure 1 illustrates the number of responses mapped to the 12 regions/zones of NHSBT ODT activity. Survey respondents collectively covered all regions across the UK, with a largest number of responses based in London (26%), Scotland (12%) and the Midlands (11%). Table 1 includes an overview of respondent characteristics. The majority of respondent were employed as nurses (nurse, specialist nurse, transplant nurse) (30%), transplant physicians (24.2%) and doctors

(referring, ICU, emergency medicine) (22.3%). Most were involved with care related to kidney transplantation (57%) and based in a transplant centre offering single (24.2%) or multi-organ provision (36.3%). The respondents were experienced professionals, with most citing years in service over 11 (36.3%) or 21 years+ (48.7%).

### Impact of COVID-19 on regional organ donation and transplantation

Figure 2 illustrates the proportion of organ donation and transplant programmes that were reported to be completely or partly paused at the time of the survey. Respondents based in most NHSBT ODT regions reported a considerable degree of scaling back of activity. The least impact was reported in Northern Ireland.

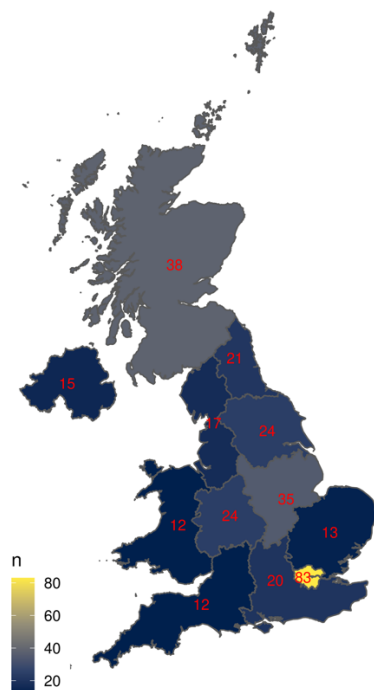
### Views on resource allocation

Table 2 displays respondent views in relation to whether or not resource allocation for transplantation has been equitable during the pandemic. There was a lack of consensus in responses to this item. Just over 32% of the study sample aligned to an inequitable response for resource allocation, with 28% stating that allocation had been equitable. There was a cluster of respondents who felt that issues related to equity are not relevant in a pandemic situation (17%), with a further cluster undecided or not providing a response to this item. Table 3 further illustrates the most important principles of equity to respondents themselves for resource allocation during the pandemic. Overall, there were distinct priorities related to maximizing the number of quality adjusted life years (QALYs) (37.9%); saving the greatest number of lives (37.6%); proportionate rationing for life saving intervention regardless of COVID status (24.8%); and saving the greatest number of life years (21.7%).

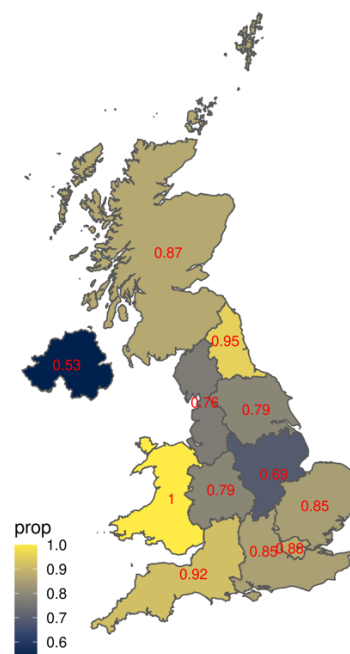
TABLE 1

	N (%)
<b>Job role</b>	
Nurse/Specialist Nurse/Transplant Nurse	94 (30)
Transplant Surgeon	30 (9.5)
Transplant Physician	76 (24.2)
Transplant Anaesthetist	2 (0.6)
Doctor (Referring/ICU/Emergency Medicine)	70 (22.3)
Infectious Disease Specialist	1 (0.3)
Pharmacist	4 (1.3)
Management/Administrative	1 (0.3)
Other	36 (11.5)
<b>Organ areas</b>	
Heart	2 (0.6)
Kidney	179 (57)
Liver	12 (3.8)
Lung	2 (0.6)
Pancreas	3 (1.0)
Small bowel	0
Deceased organ donation	69 (22)
Not applicable	36 (11.5)
Other	11 (3.5)
<b>Years of service</b>	
<5 years	8 (2.5)
6-10 years	39 (12.4)
11-20 years	114 (36.3)
21+ years	153 (48.7)
<b>Type of hospital</b>	
Transplanting centre (single organ)	76 (24.2)
Transplanting centre (multiple organ)	114 (36.3)
Non transplanting centre with transplant follow up	65 (20.7)
Non transplanting centre	59 (18.8)

Number of answers to the survey by Region



Proportion of programs paused completely or in part.



**Table 2: Views on equity in resource allocation**

	N (%)
Inequitable. The needs of critical non-COVID patients have been overlooked.	21 (6.7)
Inequitable, but transparent. Pandemic planning reasonably and transparently prioritises “saving the greatest number of lives”.	80 (25.5)
Equitable. Health systems are designed to be responsive to the needs of society.	14 (4.5)
Equitable. Health care planning in a pandemic fairly, reasonably and transparently prioritises “saving the greatest number of lives”.	74 (23.6)
In a pandemic, issues of equity are not relevant. We need to manage the crisis.	53 (16.9)
Undecided	27 (8.6)
Missing	45 (14.3)

**Table 3: Principles of equity important to respondents personally**

	N (%)
Saving the greatest number of lives.	118 (37.6)
Saving the greatest number of life years.	68 (21.7)
Maximising the number of quality adjusted life years (QALYs).	119 (37.9)
Prioritising those who have particular instrumental value to others during the pandemic.	17 (5.4)
Reciprocity. Prioritising those who have given to society.	6 (1.9)
Prioritising those who experience inequalities in access to healthcare.	12 (3.8)
First-come-first served.	3 (1.0)
Sickest first.	61 (19.4)
Youngest first.	21 (6.7)
Proportionate rationing for life-saving interventions regardless of Covid-19 status.	78 (24.8)
Random selection when considering patients with similar prognosis.	5 (1.6)
Other	8 (2.5)

**Absolute criteria for organ donation and transplantation during COVID-19**

Table 4 displays responses to absolute criteria that respondents felt were necessary for organ donation and transplantation to continue during COVID-19. The most common criteria included the donor (77.7%) and recipient (74.8%) screening negative for COVID-19 infection, post-operative critical care capacity (71.3%) and the transplanting hospital having a COVID-19 free pathway (67.8%). It is notable that a range of other criteria were important to at least 30% of respondents such as rate of transmission in the region where the transplant is taking place (44.6%), point of care testing (44.6%), segregated workforce (36.3%) and family residing in the same house screening negative for COVID infection at the time of grafting (30.6%).

**Organ donation and transplant community response during the pandemic**

Table 5 includes responses to key learning about what the organ donation and transplant community has done well during the pandemic. Statements with the highest endorsement

included that the community had acted responsibly and proportionately (51.6%), provided access to up to date information and data (43.9%), communicated risk (40.8%), and provided access to information through webinars (36.3%). To a lesser extent, respondents agreed that national oversight of transplantation was responsible and decisive (23.6%), the transplant community overall was decisive (25.8%), the community has acted regionally (27.4%) and supported research into COVID-19 (25.8%).

**Table 4: Endorsement of absolute criteria for organ donation and transplantation**

	N (%)
Low transmission rate of Covid-19 in region where transplant is taking place	140 (44.6)
Transplanting hospital has a Covid-19 free pathway	213 (67.8)
Transplanting hospital is a “green site”	55 (17.5)
Post-operative critical care capacity	224 (71.3)
Availability of segregated workforce	114 (36.3)
Potential transplant recipient has low post-operative risk	154 (49)
Potential transplant recipient has high risk of waitlist mortality	114 (36.3)
Donor Covid-19 infection screen negative	244 (77.7)
Recipient Covid-19 infection screen negative	235 (74.8)
Healthcare staff Covid-19 infection screen negative	102 (32.5)
Carer/family in the same home as recipient Covid-19 infection screen negative at the time of grafting	96 (30.6)
Availability of point of care testing for Covid-19	140 (44.6)
Availability of effective treatment for Covid-19	29 (9.2)
Availability of Covid-19 vaccine	10 (3.2)
Don't know	7 (2.2)
Other	15 (4.8)

**Table 5: Strengths of countrywide response to COVID-19**

	N (%)
The transplant community has communicated risk associated with Covid-19 and solid organ transplant	128 (40.8)
The transplant community has provided access to up to date information	138 (43.9)
The transplant community has provided access to informative webinars	114 (36.3)
The transplant community has acted decisively	81 (25.8)
The transplant community has acted responsibly and proportionately	162 (51.6)
The transplant community has acted regionally	86 (27.4)
National oversight of transplantation has been responsible and decisive	74 (23.6)
The transplant community has supported research into Covid-19	81 (25.8)
Don't know	19 (6.1)
Other	26 (8.3)

**Free text analysis**

We analysed 158 free text comments overall drawn from 115 individual respondents. Three themes emerged from the data. Table 6 details the master themes and their associated sub-themes further. *‘Pandemic preparedness’* highlighted respondent perceptions about the need for clear political stewardship to drive consistency in clinical practice. There was a sense that many decisions and practices were being implemented locally though centralised directives may have been time efficient and led to more consistency in patient management. Related to this, respondents felt that services could have been reconfigured more rapidly to preserve activity. Sharing knowledge was seen as a significant strength to navigate uncertainty.

The second theme related to *‘inequity in resource allocation’* driven by a perception of disproportionate resource distribution to COVID-19 leaving patients impacted by end stage organ failure marginalised. There was also recognition that where transplantation was being supported, there is potential for disparity since these centres may be prioritising their own patients as opposed to looking collectively at fair access and allocation.

The third theme related to *‘personalised care’* and referred to both the risk-benefit approach to organ donation and transplantation to address the tension of disadvantaging those in need of urgent intervention balanced with ensuring that patients are fully aware of added risks during the COVID pandemic.



Table 6: Thematic analysis of free text comments

Master Theme	Sub-themes	Quotes exemplifying meaning
<b>Pandemic preparedness</b>	Clarity in healthcare stewardship	<p><i>"There has been a lack of direction at a national level, with much of the responsibility being left to local units to determine."</i></p> <p><i>"I think that some of the decisions could and should have been more centralised -this would have saved time in units all writing their own policies and letters and also would have provided greater equality for access to transplantation."</i></p> <p><i>"It is an ever changing situation and people are required to be flexible to move quickly with the changes but this requires clear communication."</i></p>
	Responsive adaptation practice	<p><i>"Think of areas within a selected transplant centre or a transplant centre that can be kept free of admissions from infectious disease of concern. Plan this at the beginning of the outbreak."</i></p> <p><i>"Aim to keep local hospital/transplanting centre within regions COVID free. Allows potential transplantation to take place."</i></p>
	Power mobilising knowledge	<p><i>"The webinars have provided good anecdotal personal experience that helps support and educate staff in less affected areas."</i></p> <p><i>"The webinars and teleconferences have been informative and influential in our decision making'."</i></p>
<b>Inequity in resource allocation</b>	Collateral damage from all eyes on COVID	<p><i>"People are now dying of the wrong disease. We have become so focused on COVID that the mortality of those with organ failure is bound to become excessive."</i></p> <p><i>"The hidden cost of the COVID pandemic will be all life threatening conditions which will have increased their mortality rates and the lack of transplantation for end organ failure as a treatment."</i></p> <p><i>"We over resourced care towards COVID-19 at the cost of donation and transplantation."</i></p>
	Consensus on fair access and allocation	<p><i>"I am interested in how certain centres have continued renal transplantation from donation after circulatory death at a time when other units across the UK have halted all but nonurgent transplantation due to the massive risk of outbreak. Is this resource allocation fair?"</i></p> <p><i>"If another surge happens, units in areas with low prevalence should not be allowed to transplant as many of their "own" patients as possible whilst other units are closed - they should offer to transplant prioritised patients from all UK units; these patients were at a complete disadvantage during the first surge."</i></p>
<b>Personalised care</b>	Individual need	<p><i>"Consideration on a personalised level for each individual in light of the unique donor offer at that point in time is crucial. For some, but not all patients transplanting during an infectious disease outbreak will be appropriate for them."</i></p> <p><i>"Keeping transplantation going at a small scale for truly needy sicker recipients has been very helpful to the institution and to these patients."</i></p>
	Patient consent and risk acceptance	<p><i>"Risk cannot be removed and provided patients are appropriately consented it is up to them to decide."</i></p> <p><i>"A degree of increased risk needs to be accepted and fully informed consent principles should be applied."</i></p> <p><i>"Importance of communicating clearly with patients regarding the risk and benefits, particularly with regards to risk of covid 19 on immunosuppression as part of consent process."</i></p>

## DISCUSSION

This study was undertaken during May/June 2020 when the UK had implemented national restrictions and was passing through its first surge in daily COVID-19 cases. Through an online survey we aimed to explore the perspectives of healthcare and administrative/managerial professionals working in organ donation and transplantation on the countrywide response. Our findings evidence the immediacy of impact on patients awaiting a solid organ transplant, and this is reflected worldwide [11-13]. Survey respondents covered all NHSBT ODT regions and reported either completely pausing activity, or a marked scaling back. The only notable exception was Northern Ireland, where data have since shown a record number of kidney transplants by September 2020. This mainly reflects the rapid set up of post-operative care within a new location to reduce risk to patients during this critical period; allowing healthcare teams to divert organs to local waitlist patients. This exemplifies the effective implementation of at least two of the absolute criteria for organ donation and transplantation that were also identified by the survey respondents, namely post-operative care capacity as well as a COVID-free pathway. Additionally, as the pandemic has progressed, the other major criteria suggested by our respondents have already transpired in emerging guidelines and practice [14-16].

Importantly, respondents expressed mixed views as to whether resource allocation for organ donation and transplantation had been equitable. Emanuel et al [17] state that there are four ethical values that drive resource allocation in times of scarcity. They relate to maximisation of benefit, treating people equally, instrumental value and priority for the worst off. Respondents in our study predominantly aligned to the ethical value of maximising benefit, which is advanced as the most important feature of responsible stewardship through a crisis [17]. Qualitative comments suggest that perceptions of how this is achieved likely reflect whether or not resource allocation was deemed as equitable or not. Inequity centred around the hidden cost or collateral damage from prioritising patients with COVID infections and concerns over disparity in decisions that allow location based priority where transplantation is viable. In other words,

reservations about how the value of maximisation applies fairly across patients. Whilst it is recognised that health services acted quickly to create capacity for an unanticipated threat [18], the NHS has a responsibility incumbent upon it to address disparity and avoid the widening of health inequalities [19]. Pandemics rarely affect all people in the same way [19,20,21]. As a consequence of the response, not only is essential life-saving care interrupted but so also are programmes and interventions focussed on improving equity, diversity and inclusivity. As we progress with a national vaccination roll-out programme, it is imperative that organ donation and transplantation professionals think through the possible ways in which equitable access to organs for transplants can be restored. This is likely to involve developing new pathways of care that take account of and respond to the additional risks that COVID-19 brings to particular age groups and communities. It is essential that any such pathways are developed collaboratively and are transparent without jeopardising trust and the enterprise of transplantation as a whole.

The transplant community can be better prepared in future by learning from this pandemic, monitoring the effect, actively intervening to redress imbalances and thereby building a stronger, more equitable future, which is more resilient to new threats. For example, in relation to patients on the waitlist for a kidney transplant, COVID infection rates are markedly lower in those dialysing at home as compared to in-centre due to the advantage of shielding [22]. There is a socioeconomic gradient to uptake of home dialysis modalities [23,24] and so programmes aimed at addressing this disparity will yield better preparedness for different patient communities when faced with challenges in future. The specific strengths of the countrywide response should be drawn on to share knowledge of effective initiatives to address disparity and to evidence sustained commitment to acting responsibly.

Whilst our survey offered rapid insight into the views of professionals involved in organ donation and transplantation, we recognise the self-selecting nature of participation and particularly that a quarter of responses were from



professionals based in London, a region with high morbidity and mortality from COVID-19 [25]. Furthermore, the majority of respondents (57%) were involved in the care of kidney patients. Both of these factors affect the extent to which the pattern of responses can be generalised to donation and transplantation overall. Notwithstanding these limitations, our data reflect issues related to resource allocation that have been raised about the care of non-COVID patients in other health settings [26,27] and so highlight learning for future crisis situations. Data particularly signal the need for transparent frameworks for guiding decisions in allocating health resources that evidence responsible stewardship as well as advocacy for patients.

In conclusion, organ donation and transplant activity was immediately impacted by the COVID-19 pandemic. Important lessons have been learnt to inform both recovery plans and the response to future threats so that we are better able to preserve essential non-COVID related care. Ethical values should be embedded to avoid the widening of disparity in an enterprise

already grappling with the limited supply of donor organs as a constraint to allocating health resources.

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