

# Lack of Resources Declines

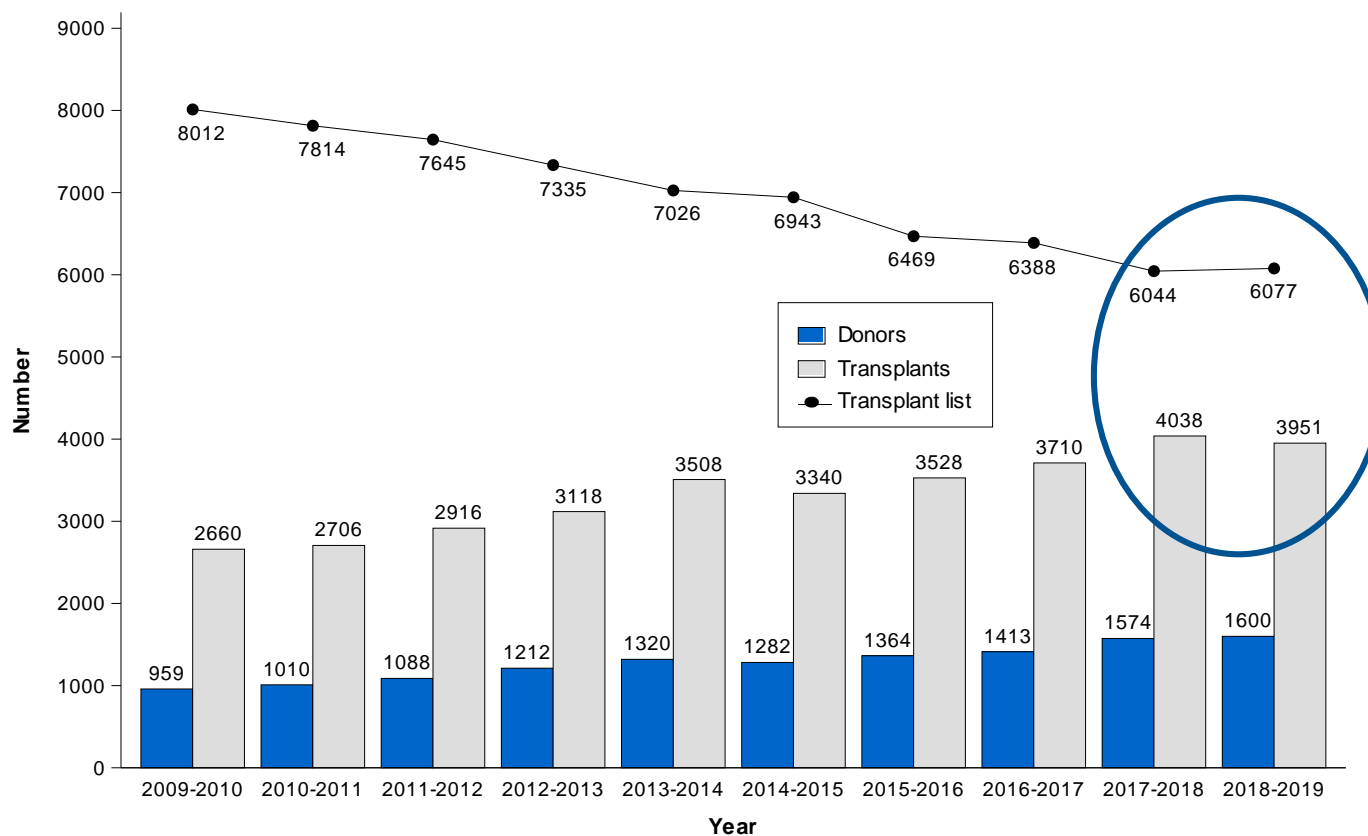
***Claire Williment***

***Head of Transplant Development***



**Yes I donate**  
ORGAN DONATION

Number of deceased donors and transplants in the UK, 1 April 2009 - 31 March 2019, and patients on the active transplant list at 31 March



Source: Transplant activity in the UK, 2018-2019, NHS Blood and Transplant

# Context



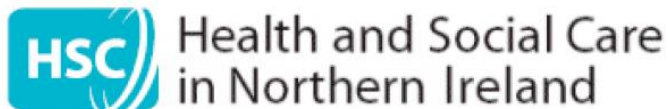
Survey of 28 transplant units estimated 90 organs declined due to lack of resources (theatres, beds, staff) in a 12 month period

- Wider NHS – Increasingly stretched and under pressure
- Improving openness and transparency about patient care
- Patients in other areas know if resources prevent access to care or therapy.
- Living kidney patients – informed if the procedure is postponed due to resource issues.
- Patient feedback – want to be able to find out if an organ was declined on their behalf purely because of resources.

NHSBT considers that there is a requirement to inform patients in circumstances where a donated organ, allocated to them by the national scheme, has been declined by the clinical team at their transplant centre solely for reasons of resource and the organ has gone on to be transplanted into another patient.

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The Voice of Transplantation in the UK



## Criteria

- Named patient offer declined
- Kidney subsequently accepted and transplanted into another patient
- Declined solely due to lack of resources.

## LoR Definition

- No beds/ staff/ theatre
- No time
- Centre closed
- Other administrative reason
- Limited theatre time
- Transport difficulties

- 1 April 2018 – 31 March 2019: 11 cases would have met the LoR Decline criteria
- All 11 cases were related to no access to beds/ staff/ theatre.



# Process

## Patient Decision

- Patient decides whether they would want to be informed of a LoR Decline
- Decision reviewed in routine patient reviews

## LoR Decline

- Kidney declined for a named patient due to lack of resources
- Data captured in standard NHSBT processes

## Notification

- NHSBT includes LoR decline in standard monthly reports to Kidney Transplant Units

## Case Review

- Unit reviews case to confirm LoR Decline criteria met
- MDT review; involvement of Organ Donation Committee where applicable

## Patient Notified

- Transplant unit reviews patient notes and if applicable, notifies the patient.

## Report

- Unit report to NHSBT about outcome of case review
- Anonymised summary provided in standard KAG papers, to inform national policies

# Patient Decision

- Right to know
- Right NOT to know
- Units make initial contact with all patients on the kidney transplant waiting list
- Decision recorded in patient notes
- Decision included as part of listing discussion
- Decision reviewed as part of regular patient review clinics.

To be printed on your Trust's Headed Paper

Dear [insert name],

**Re: New information for patients on the Kidney Transplant Waiting List**

Our hospital always strives to provide the highest level of care for our patients and to accept every suitable kidney from a deceased donor that has been offered. However, on very rare occasions, problems with resources may mean that an offered kidney from a deceased donor may have to be declined (or cannot be accepted) if certain circumstances occur.

**Information for Patients on the Deceased Donor Kidney Transplant Waiting List**

This leaflet explains the new process for informing patients if a kidney offered to them has been turned down because of lack of resources in their transplant centre. This is referred to as a 'Lack of Resources' decline (LoR decline).

**Why is this new process needed?**

We are doing more kidney transplants in the UK than ever before, with better outcomes. Last year, 2,577 kidneys from deceased donors were transplanted in the UK. The average time that patients spend waiting for a kidney from a deceased donor is coming down.

However, it is not always possible for kidney transplant centres to accept every kidney that is offered to them. Very rarely – only 11 times last year – a kidney is turned down because of lack of resources in the unit. This may be because of lack of ward or intensive care beds or because of problems finding an available operating theatre. The kidney will then be offered to another patient and transplanted.

We think it is important that patients are told if a kidney has been turned down because of lack of resources. We also know that some patients on the waiting list might find this very upsetting, and may not wish to be told about a kidney being turned down for them.

Following talks with patient representatives, there is a new requirement from NHS Blood and Transplant that patients should be given the choice about whether they'd like to be told if a kidney offered to them has been turned down because of lack of resources.

This new scheme is referred to as the Lack of Resources declines (LoR declines). The term 'lack of resources' covers problems such as no available operating theatre, no spare critical care beds, no transplant surgeon or not enough operating theatre staff available.

This approach is in line with that already taken with living donor kidney transplants, where the donors and recipients are informed if the planned surgery had to be delayed due to a lack of available resources. It is also in line with other areas of medicine, where patients are informed if they are denied access to a clinically-proven treatment or medication due to cost or resource issues.

Default: Do not inform if the patient has no recorded decision about LoR declines.



# LoR Decline Occurs

- Unit declines a kidney for a named patient
- Reason(s) recorded by NHSBT Hub Operations meet the LoR Declines definition.
- Data captured in NHSBT databases

## LoR Definition

- No beds/ staff/ theatre
- No time
- Centre closed
- Other administrative reason
- Limited theatre time
- Transport difficulties

# Notification

- Automated process for flagging declines that meet the LoR Declines criteria
- LoR Decline highlighted in monthly reports sent by NHSBT to Units

Kidney organ offers to X, 1 December 2019 to 31 December 2019													
Donor details				Offer details							Local decline reasons		
Donor ID	Hospital ID	Donor type	Donor age	Offer date	Offer type	Kidney offered	Offered to particular patient	Highly priority recipient	Ultimate outcome of left kidney	Ultimate outcome of right kidney	Primary reason for centre decline	Secondary reason for centre decline	
143608	HK3151	DBD	58	04-Dec-19	KAS	RIGHT KIDNEY	Yes	No	transplanted elsewhere	declined by centre, transplanted elsewhere	Donor unsuitable - past history	Not reported	
143675	H11021	DCD	52	07-Dec-19	KAS	UNSPECIFIED KIDNEY	Yes	No	transplanted elsewhere	accepted by centre, not used and transplanted elsewhere	Anatomical	Not reported	
143675	H11021	DCD	52	07-Dec-19	KAS	UNSPECIFIED KIDNEY	Yes	No	accepted by centre, not used and transplanted elsewhere	transplanted elsewhere	No beds	Not reported	
143675	H11021	DCD	52	07-Dec-19	KAS	UNSPECIFIED KIDNEY	Yes	No	accepted by centre, not used and transplanted elsewhere	transplanted elsewhere	No beds	Not reported	
143740	HD0612	DBD	72	11-Dec-19	KAS	UNSPECIFIED KIDNEY	Yes	No	declined by centre, transplanted elsewhere	declined by centre, transplanted elsewhere	Donor unsuitable - age	Not reported	
143806	H11021	DCD	55	14-Dec-19	KAS	UNSPECIFIED KIDNEY	Yes	No	transplanted elsewhere	accepted by centre, not used and transplanted elsewhere	Donor unsuitable - past history	Not reported	
143957	HT0201	DBD	47	24-Dec-19	KAS	UNSPECIFIED KIDNEY	Yes	Yes	not transplanted	accepted by centre, not transplanted	Recipient refused	Not reported	
143954	HC0886	DCD	69	24-Dec-19	KAS	UNSPECIFIED KIDNEY	Yes	No	declined by centre, transplanted elsewhere	declined by centre, transplanted elsewhere	Donor unsuitable - past history	Other	
144053	HD0612	DBD	72	31-Dec-19	KAS	UNSPECIFIED KIDNEY	Yes	No	declined by centre, transplanted elsewhere	declined by centre, transplanted elsewhere	Donor unsuitable - past history	Not reported	

Note: only includes offers declined by centre that went on to be transplanted, or accepted by centre but not transplanted/transplanted elsewhere.  
This reports on kidney only offers, any offers for simultaneous kidney and pancreas transplants are included in the pancreas reports.  
Kidneys offered and then withdrawn are excluded from this report. An offer can be withdrawn if there was no response to a fast track offer, or a fast track offer was accepted but the organ was given to another centre.  
Offers highlighted in red are those where the recipient of the offer was highly sensitised (100%) or a long waiter (>= 7 years) or has a matchability score=10.  
Offers highlighted in blue are those where organs were declined solely due to a lack of NHS resources (e.g. no bed/ theatre/ staff available). NHS Blood and Transplant expects that a transplant centre will inform patients in circumstances where a donated organ, allocated to them by the national scheme, has been declined by the clinical team at their respective centre solely for these reasons.  
Offers for recipients that were either highly sensitised (100%), a long waiter (>= 7 years) or with matchability score=10 that were declined solely for a lack of NHS resources are highlighted in red except the decline reason columns (T and U), which are highlighted in amber.

In the event of an offer having been declined solely due to a lack of NHS resources, please report back to NHSBT via the online survey at the link below:  
<https://www.surveymonkey.co.uk/t/LoRDecline>

If you have any queries, then please get in touch via the email address below:  
LoRDeclines@nhsbt.nhs.uk

# Notification

- Automated process for flagging declines that meet the LoR Declines process
- LoR Decline highlighted in monthly reports sent by NHSBT to Units

Kidney organ offers to X, 1 December 2019 to 31 December 2019				Reasons	
Donor details				Secondary reason for centre decline	
Donor ID	Hospital ID	Donor type	D	reported	
143608	HK3151	DBD		reported	
143675	H11021	DCD		reported	
143675	H11021	DCD		reported	
143675	H11021	DCD		reported	
143740	HD0612	DBD		reported	
143806	H11021	DCD		reported	
143957	HT0201	DBD		reported	
143954	HC0886	DCD		reported	
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# Case Review

- Was the LoR Declines notification correct?

## No

- Notify NHSBT via survey
- Confirm correct reason for decline

## Yes

- MDT case review to identify causes.
- Agreement regarding local or national action required to prevent re-occurrence.
- Local Organ Donation Committee involved where applicable.
- Senior Trust management alerted where applicable.

# Patient notified

- Patient case notes reviewed to determine whether there is a recorded decision to be informed of a LoR Decline notification
- NO or NO RECORDED DECISION:
  - Continue with local action
  - Report to NHSBT via standard route
  - Do not inform the patient
  - Include case review in patient notes
- YES:
  - Contact the patient in line with local agreed approach
  - Explain the case and outcome of the case review
  - Provide advice on where they can access support

# Report

- NHSBT on-line survey:
  - Feedback about the case
  - Feedback about patient reaction
  - Feedback about the process
- Response collated by NHSBT ODT Clinical & Support Services
- Responses reviewed by ODT Stats & Clinical Audit Team
- Anonymised responses included in Kidney Advisory Group report provided by Stats & Clinical Audit Team
- Feedback where appropriate to Commissioners, Government etc.

## NHSBT On-Line Survey

1. Disciplines of people involved in the case review
2. Was LoR Decline criteria met?

### IF YES:

2. Informing the recipient
3. Action taken/ planned at a local level
4. Action required at a national level
5. Any other comments
6. Feedback about the LoR Declines process





# Progress to date

- October 2019 – Notification data started being collated
- November 2019 – Report issued, with link to response survey
- Automated system working effectively (currently also manual checking to ensure no inappropriate/ missed notifications).
- 9 notifications where LoR criteria was met in the period 01/10/2019 – 31/12/2019
- No responses yet received to a LoR notification via survey.

# Next steps

- February 2020 – Deadline for first Response Survey from any notifications
- Data included in Kidney Advisory Group standard reports and lessons learned/ actions required taken forward as appropriate.
- July 2020 – Formal review of LoR Declines process
- Autumn 2020 onwards – Subject to review outcomes, potential roll-out to other organs

# Summary

- LoR process established following feedback from patient groups and transplant units and in consultation with Government and UK Commissioners.
- Balances the patient's right to be informed against their right not to know. Decision rests with the patient.
- Strengthens patient information and supports local negotiations for resources within Trusts
- Well received and supported.

**Thank you**

**Questions?**