

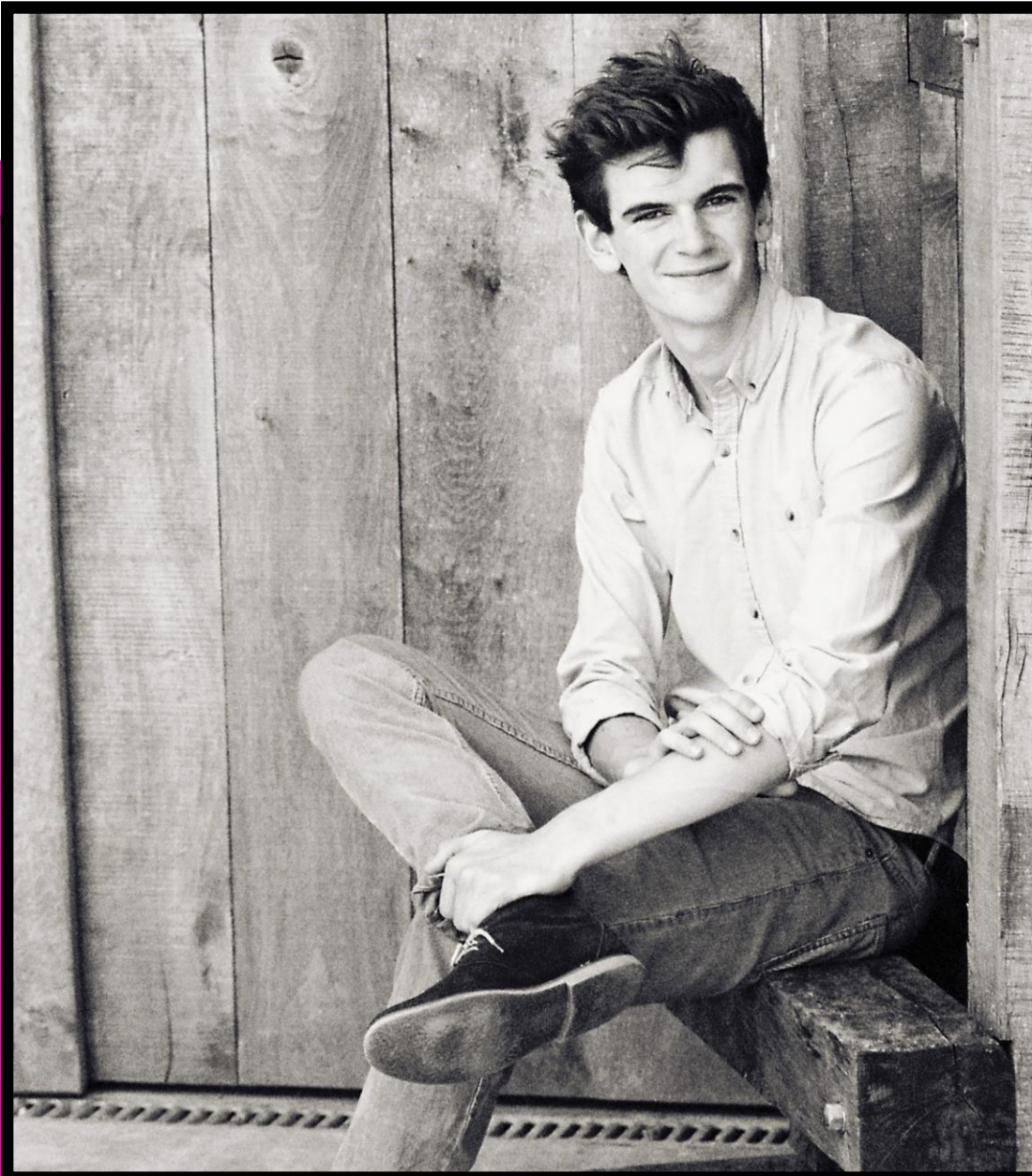
# Improving Communications between Recipients & Donor Families

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British Transplantation Society Congress 2018



University Hospital  
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NHS Foundation Trust

### Will Houghton

"Will was a bright, loving, inquisitive and motivated young man with a love of family, the outdoors, the sea and cycling. He always wanted to experience the very most life had to offer and inspired those around him to do the same. Knowing that his precious organs and tissue have saved the lives of over eight people gives great comfort to all his family and friends."

*Liz and Richard,  
Will's parents*



Yes I donate  
ORGAN DONATION

“Positive recognition and acknowledgement of donors is a vital aspect of NHSBT’s agenda to change public attitudes towards organ donation.”

(NHSBT Taking Organ Transplantation to 2020 strategy)

Promote the most positive experience of donation



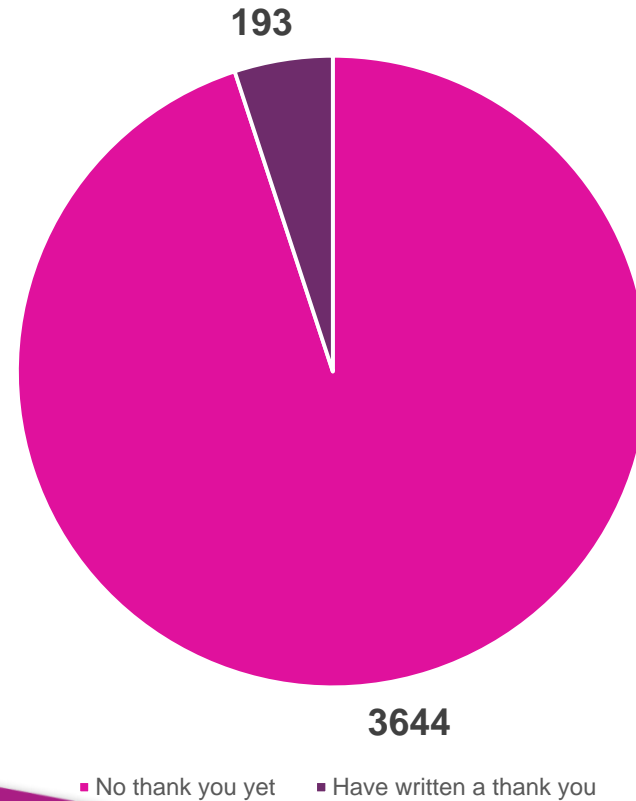
Donor Family as ambassador for the process

More organs for transplant

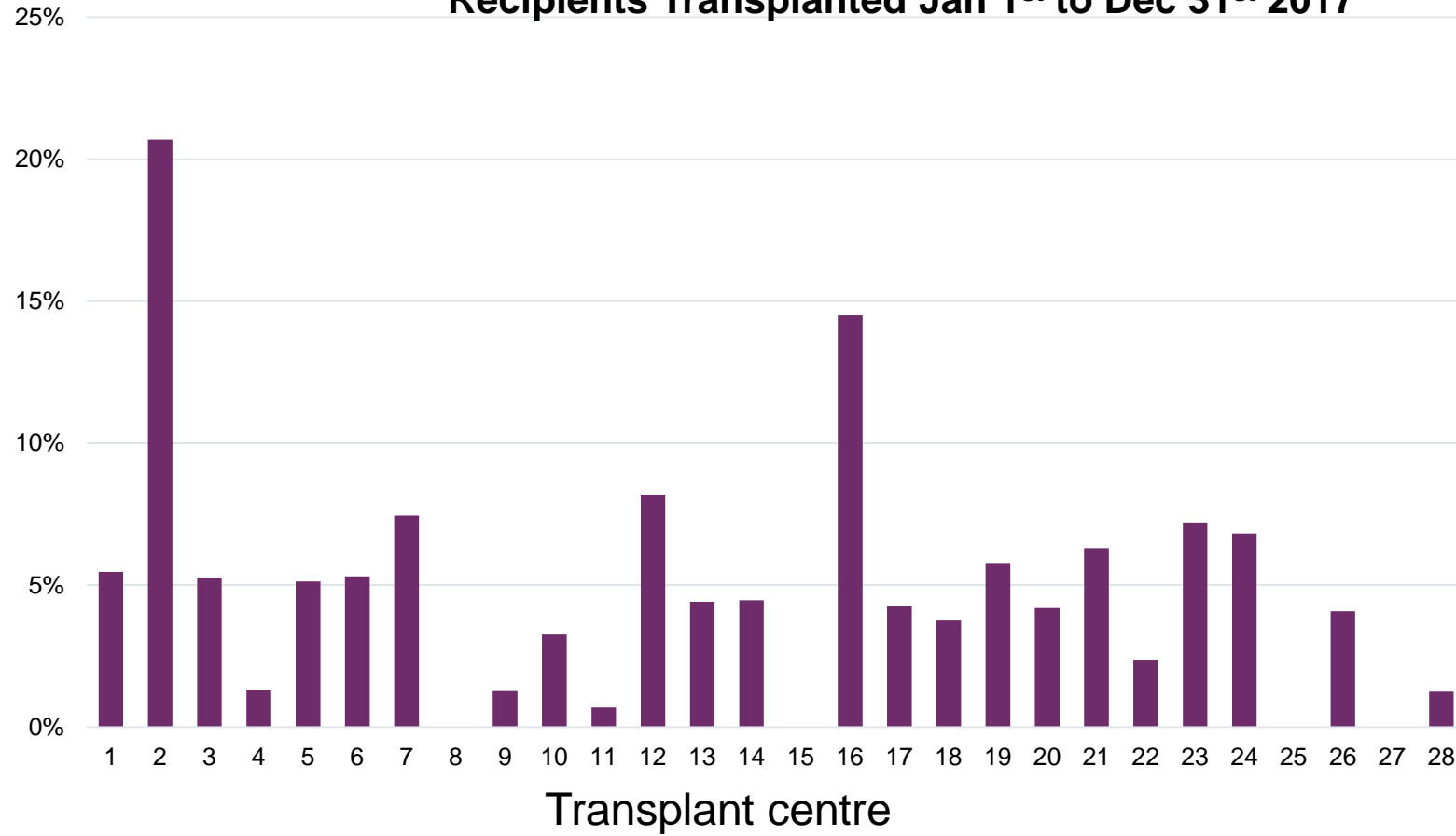
# The Statistics

Just 5.3%

Transplants in 2017



## Recipients Transplanted Jan 1<sup>st</sup> to Dec 31<sup>st</sup> 2017



Survival rates and types of transplant are not factored into this analysis

# The Positivity of a Thank You



Blood and Transplant

## Donor Family Perspective

- Appreciation
- Sense of pride
- Recognition of donor legacy
- Reaffirms positivity of decision to donate

## Recipient Perspective

- Acknowledgement
- Outlet for gratitude
- Relief of unwarranted guilt
- Closure

# PhD Research: 'The Emotional Management of Suffering during the Transplantation Process'

- Methodology: Semi-structured interviews and observation
- Sample Demographics: Organ Transplant Recipients
  - 14 males, 4 females
  - Age range 26-75
  - 13 deceased donation
  - 5 live donation
  - 8 kidney recipients
  - 8 liver recipients
  - 1 pancreas recipient
  - 1 heart recipient



# Findings-

## Recipient Letter Writing/Exchanges (Deceased Donation)

- Mixed feelings about letter writing and potential contact with donor families
- 4 key sub-headings
  - Recipients who wrote with no response from the donor family (n=5)
  - Recipients wrote but did not want a response (n=7)
  - Recipient wrote a letter and met with their donor family (n=1)
  - Recipient who had received 4 transplants has never thanked donor family (n=1)

# How can Sociology make sense of this?

## The Paradoxical Nature of Transplant

- Individuals have their own **personal expectations** from what they expect from writing/contact with donor families.
- The letter writing process is
  - **complex**
  - creates levels of **anxiety**
  - **ambiguous**
- Recipients are unsure as to when is the **right time** to write

# In Summary

Recipients are unsure or do not write a thank you letter because of the following factors:

- Uncertainty regarding whether the donor family would like to hear from them
- They need more help on writing the letter
- They feel the letter highlights the loss of the donor family and makes recipients feel guilty
- A complicated and emotional transaction. Not a straightforward process.

# What can NHSBT do?

- Manage expectations of the donor families
- Take onus off 'letter writing' and facilitate other means of acknowledgement
- Simplify the process - more clear cut and less ambiguous
- Feedback the data to transplant centres
- Survey on-going to understand reasons why recipients don't write
- Support the development of best practice guidance

# How you can help us?

- Make it normal and expected to say thank you to the donor's family
- Provide as much information as the recipient will allow when asked for updates.
- Signpost the website <https://www.odt.nhs.uk/information-for-patients/donor-family-and-recipient-contact/>
- Keep asking...families keep hoping



‘It is now thirteen years since we agreed, at the moment of utmost grief, that David’s organs could be removed for transplant. We were told a few weeks later that his liver had been successfully transplanted... A simple thank you from the recipient and a sign of interest in the origin of his extremely fortunate gift would help to keep our son with us in soul and in spirit.’

*Alick & Penny*