

**Department of Health  
& Social Care**

**ISOU Transplant Commissioning  
Symposium**

Robbie Burns

6 November 2024

Cardiothoracic Transplant Patient  
Group Chair, NHSBT

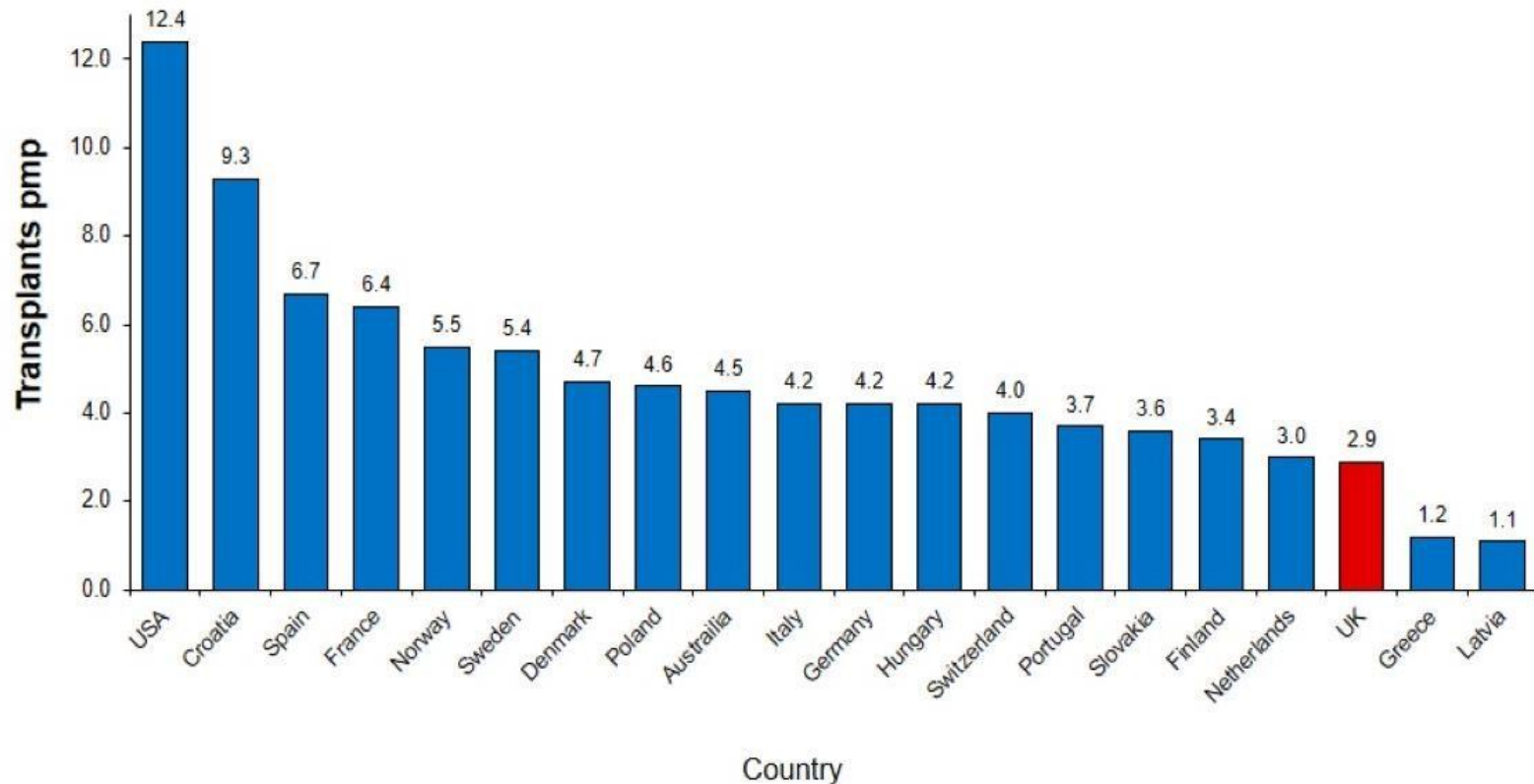
Heart Transplant Recipient

# Content

- Is CT transplant commissioning working?
  - Access
  - Clinical outcomes
  - Patient experience
- Summary
- Reflections
- Commissioning – patient perspective

# CT Transplant Access – Heart Transplant Rates

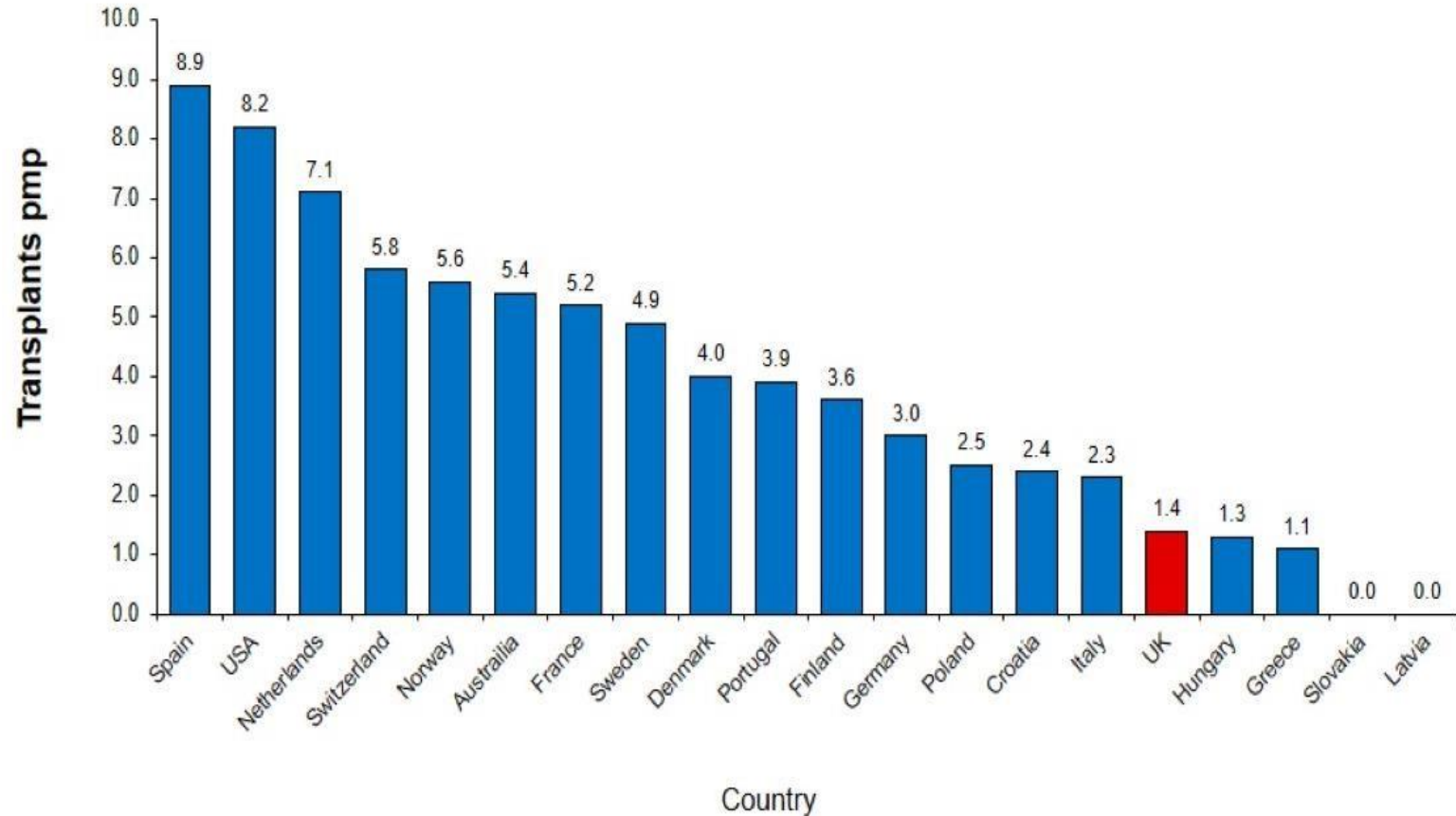
Heart transplant rates for Europe, Australia and the USA, 2022



Source: Council of Europe – Transplant Newsletter

# CT Transplant Access – Lung Transplant Rates

Lung transplant rates for Europe, Australia and the USA, 2022



Source: Council of Europe – Transplant Newsletter

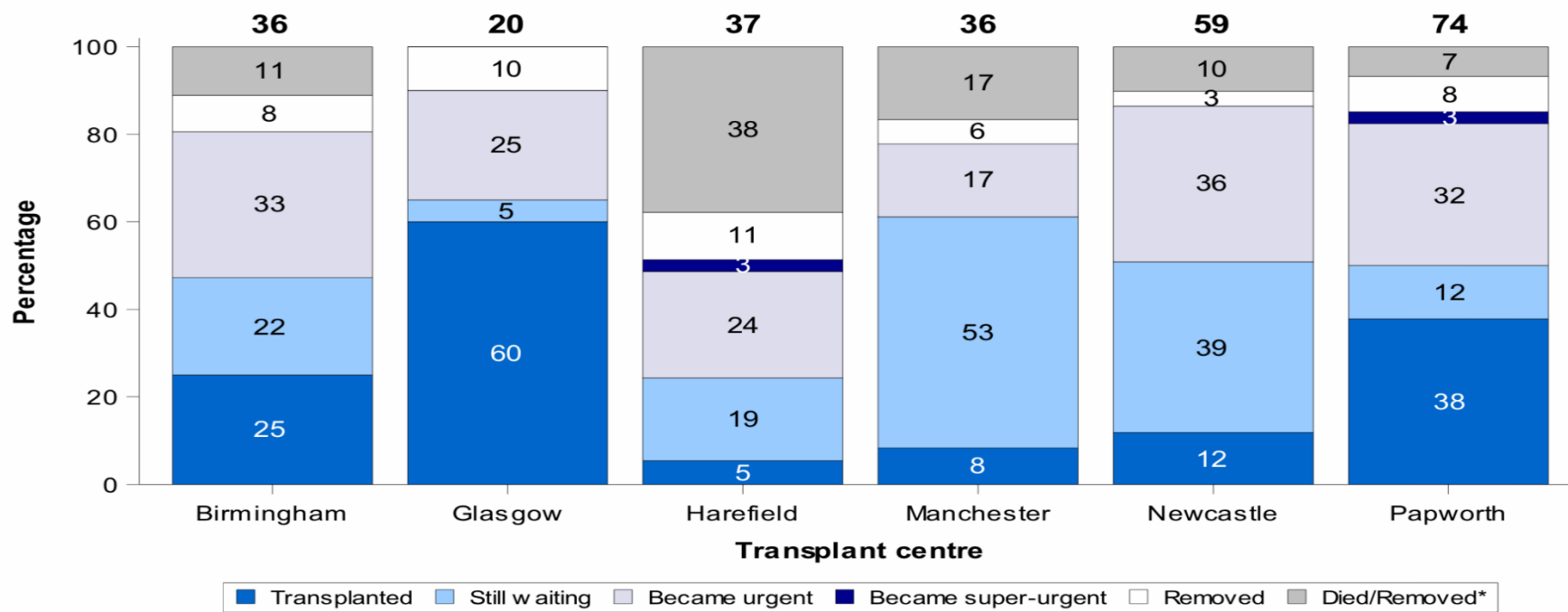
# CT Transplant Access – Heart Variation

17:24 Tue 29 Oct

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100%

**Figure 3.6 3 year post-registration outcomes for 262 non-urgent heart only registrations made in the UK, by centre, 1 April 2019 to 31 March 2021**



\*Removals due to condition deteriorating

Source: NHSBT Annual Heart Transplant Report 2023/24

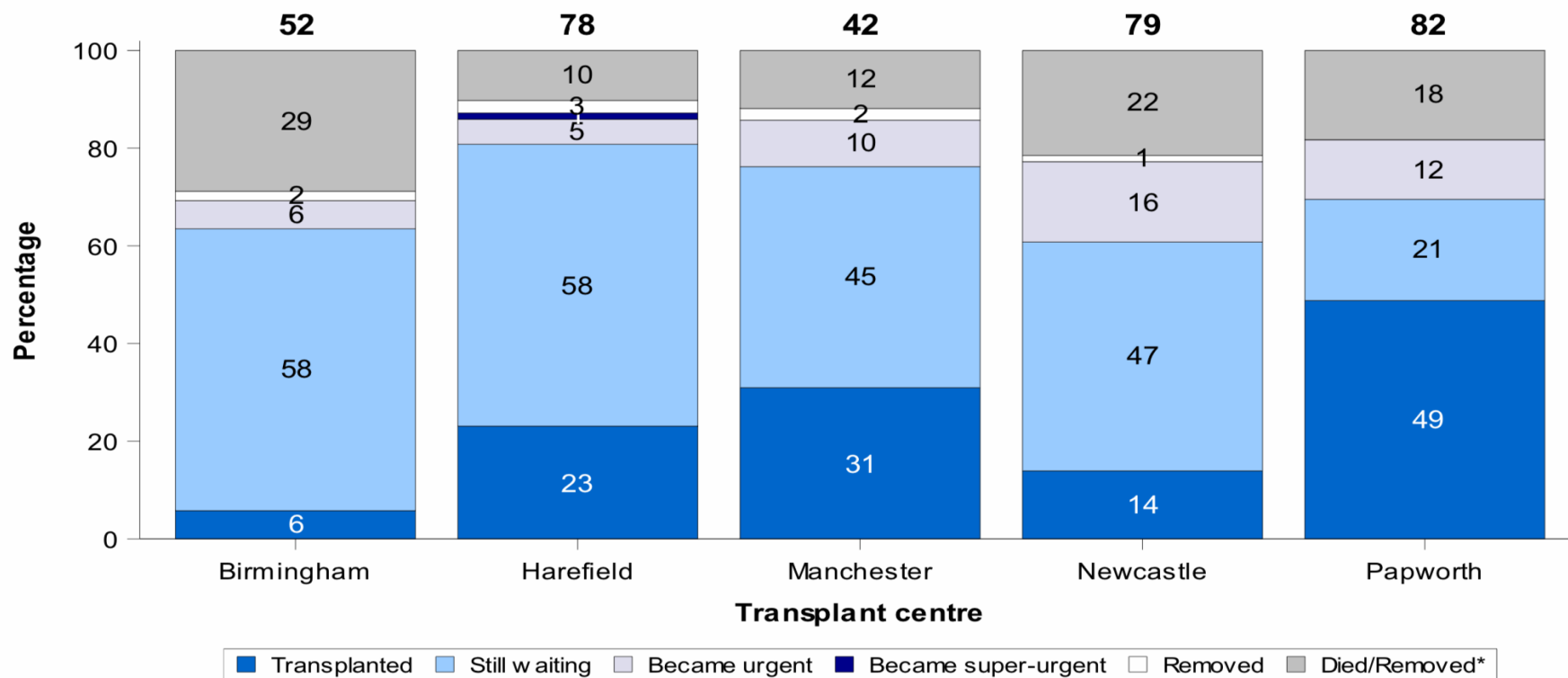
# CT Transplant Access – Lung Variation

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100%

**Figure 3.5 1 year post-registration outcomes for 333 non-urgent lung only registrations made in the UK, by centre, 1 April 2019 to 31 March 2021**



\*Removals due to condition deteriorating

Source: NHSBT Annual Lung Transplant Report 2023/24

# **CT Transplant – Paediatric Access**

- Median Urgent Heart Transplant waiting times (1 April 2020 – 31 March 2023)
- **Adults 43 Days**
- **Children 204 Days**
- Source NHSBT Annual Heart Transplant Report 2023/24

# CT Transplant Outcomes – Adult Hearts

| 1 Year Mortality |       |
|------------------|-------|
| Era              | UK    |
| 2011-15          | 17.2% |
| 2015-19          | 16.8% |
| 2019-23          | 12.3% |

Source – NHSBT Annual Heart Transplant Reports

# CT Transplant Outcomes – Adult Hearts

| 1 Year Mortality |       |        |
|------------------|-------|--------|
| Era              | UK    | Sweden |
| 2011-15          | 17.2% | 5.4%   |
| 2015-19          | 16.8% |        |
| 2019-23          | 12.2% |        |

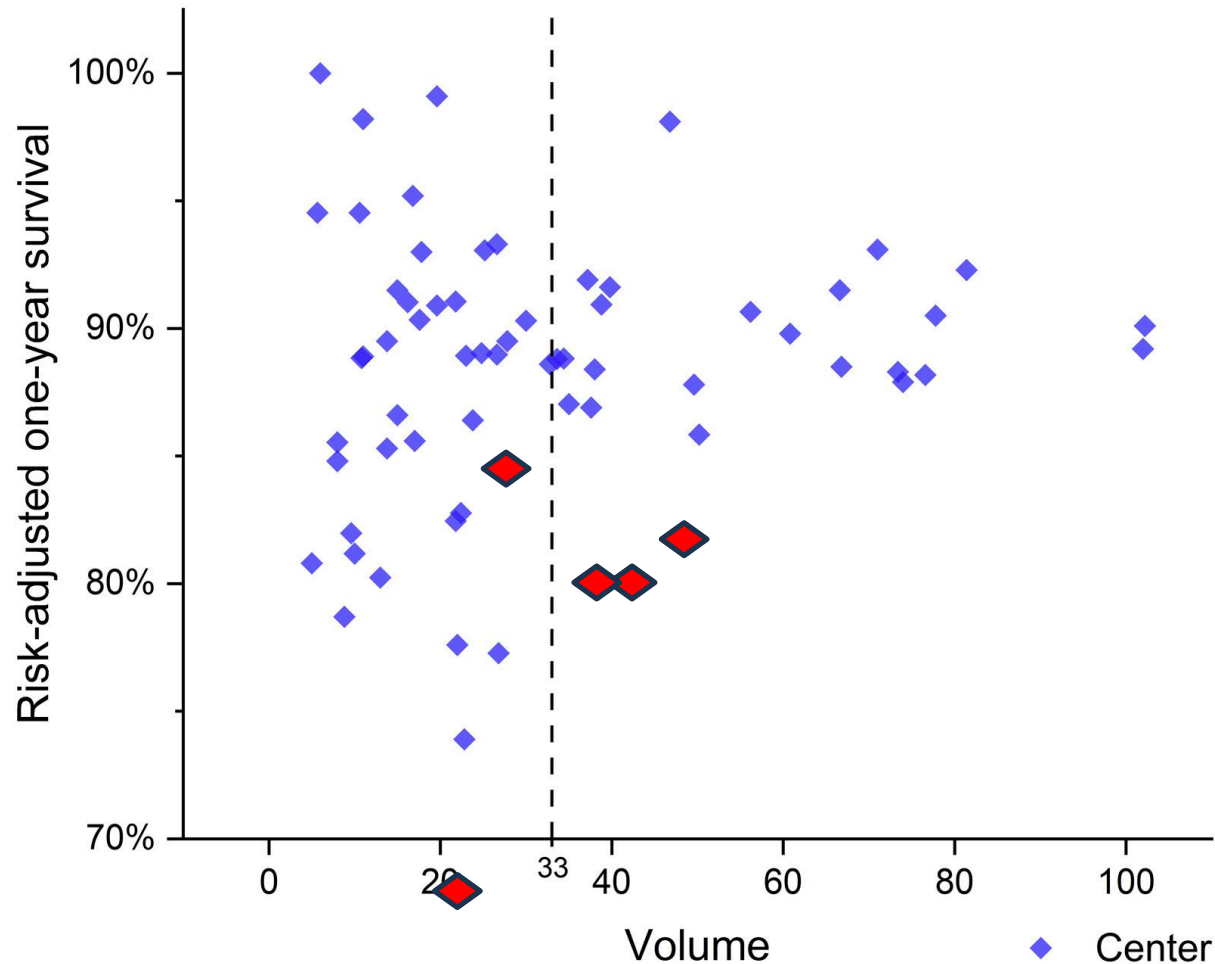
## Median Donor Age

UK – 35

Sweden - 48

Source Gjesdal et al, “Waiting list and post-transplant outcome in Sweden after national centralization of heart transplant surgery”, Journal of Heart and Lung Transplantation, 2024

# CT Transplant Outcomes – Adult Lungs



Sources – NHSBT Annual Lung Transplant Reports & Yang et al, “The Impact of Center Volume on Outcomes in Lung Transplantation”, The Annals of Thoracic Surgery, 2022

# CT Transplant Experience

| Healthcare Process                                | Net Postive |
|---------------------------------------------------|-------------|
| FFT Hospital Inpatient                            | 93%         |
| FFT Community                                     | 93%         |
| Being contacted to say organ available            | 92%         |
| FFT Hospital Outpatient                           | 91%         |
| Being prepared for surgery                        | 89%         |
| The operation                                     | 89%         |
| FFT GP                                            | 88%         |
| FFT Maternity                                     | 87%         |
| Info about medication                             | 85%         |
| Care in hospital following the operation          | 84%         |
| Being discharged                                  | 84%         |
| FFT Mental Health                                 | 81%         |
| Info about future assessments                     | 80%         |
| Info about possible complications after discharge | 79%         |
| FFT Ambulance                                     | 77%         |

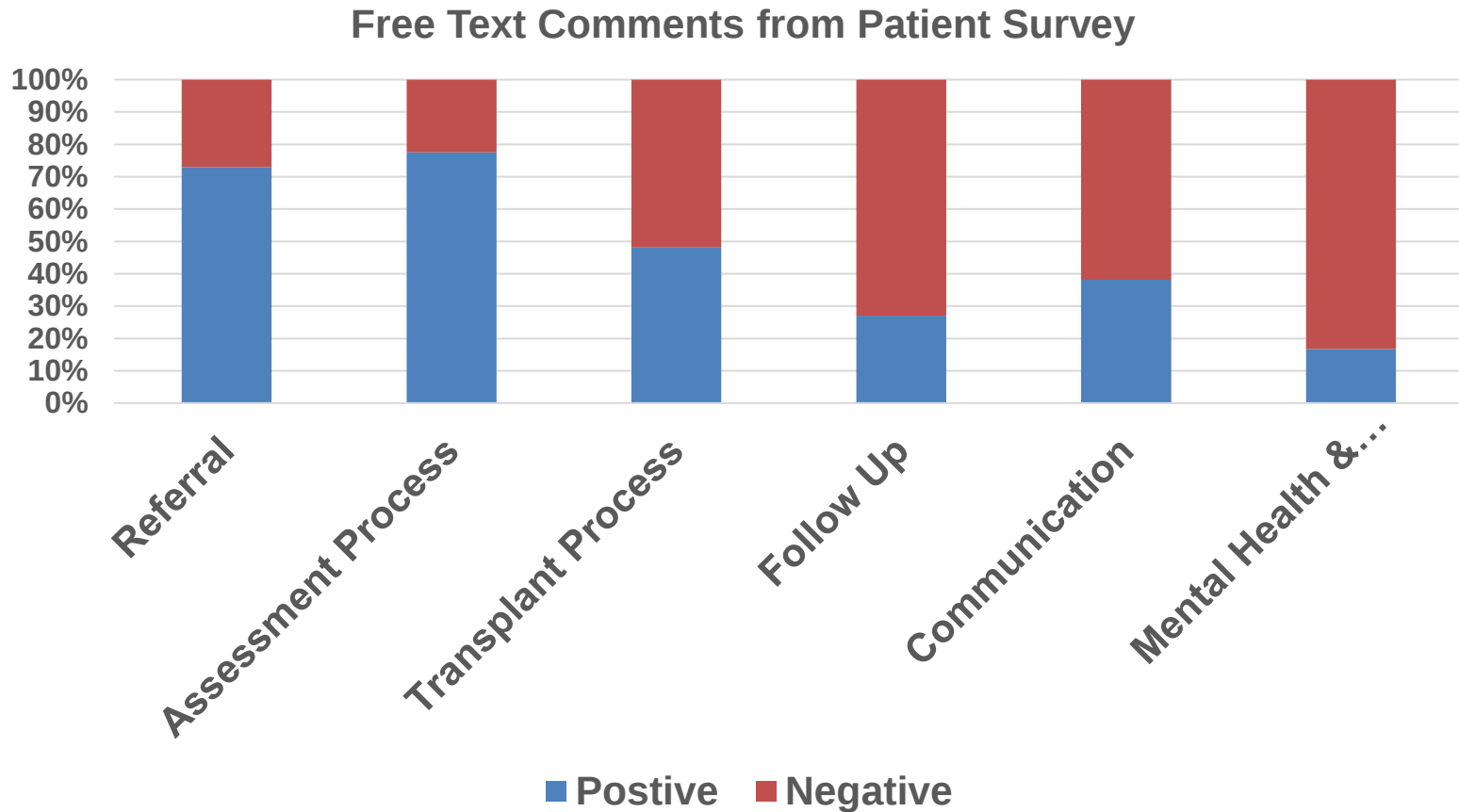
| Healthcare Process                                                                                         | Net Postive |
|------------------------------------------------------------------------------------------------------------|-------------|
| How well do you think the transplant centre communicated with you/the patient?                             | 76%         |
| FFT A & E                                                                                                  | 72%         |
| Emergency advice                                                                                           | 67%         |
| Overall health support                                                                                     | 64%         |
| Patient advice line                                                                                        | 60%         |
| Side effects of medicine                                                                                   | 58%         |
| How well do you think the transplant centre communicated to the GP?                                        | 54%         |
| If applicable, how would you rate the communication between the transplant centre and other hospital team? | 54%         |
| Mental health support: patient                                                                             | 38%         |
| Social care support                                                                                        | 15%         |
| Mental health support: family/carers                                                                       | 3%          |
| Advice through GP                                                                                          | -1%         |
| Fertility advice                                                                                           | -6%         |

|                      |
|----------------------|
| FFT Reference        |
| Transplant Admission |
| Transplant Advice    |

|                                       |
|---------------------------------------|
| Transplant Communication              |
| Transplant Health / Wellbeing support |

Sources – CT ICE Patient Survey & NHSE Friends & Family Test August 2024

# CT Transplant Experience



Source: CT ICE – Patient Survey – Free text comments – survey stage

# Summary

- Access – poor, very poor in lungs
- Clinical outcomes - moderate to poor
- Patient experience – moderate in acute phase and poor in follow up

# Summary

- Cardiothoracic Transplant  
Services in England are broken.....

# Reflections ..... but there are positives

- Excellent organ donation teams and rates are good
- DCD heart transplant programme world leading (29% adult heart transplants)
- World leading research; £20m NIHR BTRU, E-CLAD UK, SENTINEL, SIGNET
- Examples excellent practice - psychology services (Glasgow) & Social Work (Manchester)
- Scotland delivering heart transplant rates over double England.

# **Reflections ..... and opportunities**

- Exceptionally engaged patient population
- Highly skilled and dedicated clinical teams
- OUG & CT ICE Reports & Recommendations
- CT Transplant Transformation Programme

# Reflections

- Cardiothoracic Transplant  
Services in England are broken.....  
.....but they are not beaten

# Commissioning – Patient Perspective

1. Commission for strategic goals (world class care) - not historical / iterative basis
2. Be bold and innovative
  - Quality - best practice tariffs, e.g. post-transplant complication **prevention**
  - Decentralise some care, including **community**
  - Use technology, integrate, **digitalise**
  - Reform – increase productivity
  - Really enhance data collection
3. Commission with patients / stakeholders & clinical teams