

Cardiothoracic Transplant Service – Information Collation Exercise (CT-ICE): survey findings

Update to Cardiothoracic Advisory Group (Lung), June 2025

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Organ Utilisation Group report recommendation 5

- The Organ Utilisation Group, chaired by Professor Sir Stephen Powis, published recommendations to Government in February 2023
- Recommendation 5 of the report is:

“NHSE must undertake a comprehensive review of cardiothoracic services to ensure that services in place are sufficiently sustainable and resilient, and are able to provide the best possible outcomes for patients.”

CT-ICE

- To support this, DHSC surveyed patients and clinicians about their experiences of cardiothoracic transplant services across the UK in March/April 2024.
- Findings, along with other data from NHS Blood and Transplant and recommendations from international experts were shared with NHSE in July 2024
- Analysis of the survey was published in October 2024
- In response to patient requests, further analysis of survey findings was also published, including at Transplant Centre level and with gender and ethnicity breakdowns in February 2025

CT-ICE Patient Survey

- Conducted March / April 2024
- 604 valid responses
 - 57% male
 - 89% white
 - 62% heart, 33% lung, 5% heart & lung
 - 80% had received a transplant
- Some responses relate to care some time ago
- All centres received enough responses for publication of data except Sheffield F/U and Newcastle Paeds

Patient survey: topics covered

1. Referral to assessment waiting times
2. Information provided at assessment
3. Transplant admission
4. Lifelong care
5. Psychosocial care
6. Raising concerns

Additional analysis provides centre, sex, ethnicity level results

(1 & 2) Assessment

- 31% patients who responded reported waiting more than 3 months to be referred for assessment
- 85% of patients who responded reported receiving information about likely outcomes at assessment or when they were listed
- An average of 57% of respondents reported they were given waiting time info for all centres (ranging from 30-85%)
- An average of 40% of respondents reported being given outcome data for all centres (ranging from 10-67%)

(3) Transplant admission

- Transplant admission generally receives positive feedback from patients.
- Relatively small variation between centres

(4) Lifelong care

- Most patients are satisfied with their lifelong care
- Much greater variation between providers
- Females score slightly lower
- Black patients and those who did not declare ethnicity score much lower

Lifelong care by sex & ethnicity

Ethnicity	Overall health support	Side effects of any transplant medicine
White	4.17	4.12
Asian	4.35	3.72
Black	3.58	2.90
Mixed	4.20	4.33
Prefer not to say	2.86	2.50

Outpatient National Average 4.73 (FFT, NHSE, Dec 2024)

Sex	Overall health support	Side effects of any transplant medicine
Male	4.25	4.15
Female	4.01	4.00

(5) Psychosocial care

- Psychosocial care levels are a big concern to patients across most providers and there is a large amount of variation
 - Ratings for patient support ranged from 2.56/5 – 4.54/5
 - Ratings for support for family/carers ranged from 1.84/5 – 3.83/5
 - Ratings for social care support ranged from 2.15/5 – 4.44/5
- Strong correlation between provision and patient experience
- Females report lower levels of experience across patient support; support for family/carers and; social care
- Black patients and those who did not declare their ethnicity report much lower levels of experience

Psychosocial care by centre

Centre	Mental health support for the patient	Mental health support for the patient's family/carers	Social care support
Birmingham	2.56	1.84	2.15
Glasgow	4.54	3.55	4.44
Harefield	3.74	3.22	3.30
Manchester	4.32	3.83	3.91
Newcastle (Adult)	3.26	2.38	3.11
Papworth	3.71	2.83	2.90
GOSH	4.05	3.89	4.10

Psychosocial care by ethnicity

Ethnic Group	Mental health support for the patient	Mental health support for the patient's family/carers	Social care support
White	3.73	3.12	3.30
Asian	3.39	3.53	3.50
Black	2.90	2.50	2.44
Mixed	3.94	3.75	4.10
Prefer not to say	1.33	1.33	1.83

(6) Willingness to raise concerns

- **27% of patients** responding based on their experience across Transplant Centres included in the survey were not comfortable to raise concerns at all stages.
- This reflects a range from 13% of patients up to 42% of patients not being comfortable in raising a concern.

Progress and further reading

- Reports are published here: [Cardiothoracic transplant information collation exercise: survey analysis - GOV.UK](#)
- Data and analysis has been shared with the NHSE programme team to consider as part of its Transformation Programme
- Specific, centre level concerns have been raised by senior DHSC officials with Executive leaders in relevant Trusts. DHSC are reassured that findings have been treated with the appropriate level of concern at that level.
- Now we want to make sure that clinicians across all elements of the CT transplant journey are aware of this data and how it applies to their setting.

Thank you and any
questions?