CTAG Hearts March 2025 – Cardiothoracic Information Collection Exercise (CT – ICE): Additional Analysis of Patient Survey

1. Background

1.1 On 6 February 2025 the DHSC published further analysis from the CT – ICE Patient Survey. This provided a breakdown of several patient survey results by centre, ethnic group and sex.

1.2 The survey population covered patients and family members at any stage of the heart and / or lung transplant pathway, pre transplant, post-transplant and deceased patient families. The survey was conducted in March and April 2024.

1.3 The survey was confidential and received 604 valid responses, with 57% relating to male patients. 89% were white, 4% Asian, 3% mixed, 2% black and 2% others / prefer not to say. 62% of patients were on heart, 33% lung and 5% heart and lung transplant pathways. 485 (80%) of patients had received a transplant, with others at a pre transplant stage. Of those that had received a transplant, the date they had their operation was, 11% pre 2000, 12% 2000-2009, 48% 2010-2019 and 28% 2020 or after.

1.4 It should be noted the responses relate to episodes of care over a wide timescale. Hence the responses that are specifically about pre transplant, the acute phase of care and feeling comfortable to raise concerns may refer to services provided many years ago. It is reasonable to assume that questions around long term care, psychosocial services and fertility advice are likely to relate to recent experiences.

1.5 The DHSC, NHSE and NHSBT hold the full datasets so a breakdown by organ, pathway or era of transplant etc would be possible.

1.6 All services except for the paediatric service in Newcastle and the follow up service in Sheffield received sufficient responses for data to be presented by centre

1.7 This paper will cover the areas reviewed in the phase 2 analysis particularly noting where patient experience falls below acceptable levels or varies between providers, sex or ethnicity.

2. Referral to first transplant assessment appointment

2.1 The survey showed that across the UK 31% of patients (who knew how long they waited) waited more than 3 months from referral to their first appointment, with some reporting waits of over 1 year. The first patient survey publication split waiting times to first assessment appointment by era, the figure for 2020 onwards is 30%.

2.2 Apart from Glasgow (which had zero) all centres had 25% or more patients reporting that they had waited over 3 months for their first appointment.

2.3 The CTPG would like to see referral to first appointment time monitored, reported and a target set.

3. Information provided at assessment / listing

3.1 85% of patients who knew reported that they were given information about the likely outcome (e.g. waiting time) for them, this figure was more than 50% at all providers.

3.2 However, a much lower percentage (57% nationally) reported that they were provided with waiting time information at all centres. This varied considerably by provider with Glasgow highest at 85% and Newcastle (Adults) lowest at 30%

3.3 An even lower percentage (40% nationally) reported that they were provided with outcomes at all centres. This also varied considerably by provider with Glasgow highest at 67% and Birmingham lowest at 10%.

3.4 These figures may relate to historical assessment / listing information, information broken down by era / stage of transplant could be obtained from DHSC, NHSE or NHSBT.

3.5 The CTPG supports the OUG, ISOU and CT – ICE recommendations of the proactive provision of this information to patients at time of listing. The CTPG would welcome working with the clinical community to develop appropriate, easy to understand national templates for this information.

4. Transplant Admission – Patient Experience

4.1 Most patients reported a positive experience during their transplant admission across all centres.

4.2 The following tables shows the arithmetic mean scores by centre across each part of the admission assessed. Scores are on a standard 1- 5 scale, with 1 being very poor and 5 being very good, this is the same scale used for NHSE's Friends and Family Test (FFT).

4.3 A score of 4 should be considered the absolute minimum acceptable level. For context the latest published NHSE FFT inpatient score (December 2024) is 4.72. Scores below 4 have been highlighted in red.

Centre	Being contacted to say organ available	Being prepared for surgery	The operation	Care in hospital following operation
Birmingham	4.83	4.32	4.40	4.18
Glasgow	4.69	4.69	4.69	4.69
GOSH	5.00	4.95	5.00	4.80
Harefield	4.81	4.75	4.77	4.65
Manchester	4.90	4.85	4.91	4.80
Newcastle - Adult	4.52	4.42	4.36	4.31
Papworth	4.88	4.78	4.76	4.73

Centre	Being discharged	Information about future assessments	Information about possible complications after discharge	Information about medication
Birmingham	4.21	3.96	3.93	4.42
Glasgow	4.69	4.69	4.62	4.62
GOSH	4.85	4.75	4.70	4.80
Harefield	4.59	4.56	4.55	4.69
Manchester	4.80	4.77	4.75	4.78
Newcastle - Adult	4.18	3.89	3.93	4.16
Papworth	4.80	4.64	4.68	4.81

4.4 These figures relate to transplants undertaken over a wide time frame hence the figures may or may not be entirely representative of current patient experience.

4.5 Current patient and patient representative feedback would suggest patients are generally satisfied with their acute transplant admission.

5. Lifelong care – Patient Experience

5.1 Although most patients report a positive experience with lifelong care, the overall scores are lower than the transplant admission. There is also a much wider variation by transplant centre. For context the latest published NHSE FFT outpatient score (December 2024) is 4.73

5.2 The tables below show the scores by question and centre;

Centre	Emergency advice 24/7	Patient advice line	Comms to patient	Comms to GP
Birmingham	3.69	3.44	3.90	3.12
Glasgow	4.69	4.75	4.93	4.79
Harefield	4.42	4.21	4.51	4.06
Manchester	4.51	4.33	4.64	4.12
Newcastle (Adult)	3.28	3.05	3.43	3.02
Papworth	4.63	4.63	4.68	4.40
GOSH	4.12	4.25	4.65	3.84

Centre	Comms other hospital	Overall health support	Side effects of any transplant medicine
Birmingham	3.69	3.13	3.37
Glasgow	4.60	4.79	4.54
Harefield	4.05	4.39	4.32
Manchester	4.00	4.52	4.34
Newcastle (Adult)	3.42	3.36	3.32
Papworth	4.33	4.27	4.36
GOSH	3.82	4.25	4.30

5.3 Glasgow scores highest in every response, they are the only provider to exceed the FFT norm in any metric. The adult services at Newcastle and Birmingham score much lower than all other centres across every single patient experience metric reported. These scores are aligned to widespread feedback from patients and patient groups. GOSH scored below acceptable levels for communication with GPs and other hospitals.

5.4 Phase 2 also reported overall health support and the side effects of any transplant medication by sex and ethnicity. Female patients scored lower across both measures. Black and patients who preferred not to state their ethnicity scored considerably lower across both metrics.

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

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

5.5 For long term care it would be reasonable to assume this relates to patient's most recent experiences. Results could of course be impacted by sex or ethnicity differences.

5.6 The CTPG would request that NHSE seek action plans from providers for any metric which scores under 4.

6. Psychosocial care – patient experience

6.1 Psychosocial care experiences were consistently low across most providers.

6.2 The table below shows the scores by provider and question

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

6.3 As can be seen the patient experience of psychosocial care is unacceptable across most providers. The patient experience directly aligns with the specialist staff provision in each transplant centre.

6.4 Phase 2 also reported all three metrics by sex and ethnicity. Female patients scored lower across all measures. Black and patients who preferred not to state their ethnicity scored considerably lower across all measures.

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

Ethnic Group	Mental health support for the patient	Mental health support for the patient's family/carers	Social care support
Male	3.87	3.41	3.50
Female	3.49	2.76	3.02

6.5 The CTPG continues to advocate for urgent action to address this care deficiency. The CTPG request that NHSE inform providers they should have a minimum of 1 WTE clinical psychologist per 350 patients and 1 WTE social worker per 400 patients in the service. Patients in the service are defined as post-transplant patients in follow up + patients on the waiting list + long term ventricular assist devices not on the waiting list.

7. Raising Concerns

7.1 The phase 2 analysis split the survey results on patient's feeling comfortable to raise concerns by provider. Nationally, 27% of patients did not feel comfortable to raise concerns at all stages of their pathway. This had over a 3-fold variation by provider (13% to 42%). The table below shows the results by provider, with the national average, in ascending order (best to worst).

Centre	**Patient not comfortable to raise concerns all stages**
Manchester	13%
Glasgow	14%
Papworth	24%
Great Ormond Street Hospital	25%
Harefield	25%
UK Average	27%
Birmingham	33%
Newcastle - Adult	42%

7.2 Clearly the target for this is 0% and the CTPG do not consider any of the figures to be satisfactory. However, the two providers below the national average are extremely concerning and would request NHSE seek action plans from providers to address these issues.

8. Summary

8.1 The CT ICE Patient / Family Survey provides a rich source of feedback on patient experiences of care

8.2 It shows that satisfaction varies across the pathway with lifelong care and psychosocial support performing much worse than the acute transplant phase

8.3 The results also reveal significant variation by provider, ethnicity and sex.

8.4 The CTPG's recommendations are as follows;

- Referral to first transplant assessment appointment time is monitored, reported and a target set.

- Work with the clinical and commissioning colleagues to develop appropriate, easy to understand national templates to support patients with making informed decisions about their care at the time of listing (also referral and follow up care).

- NHSE request action plans from providers for any metric which scores under 4 in the CT ICE Phase 2 analysis.

- NHSE inform providers they should have a minimum of 1 WTE clinical psychologist per 350 patients and 1 WTE social worker per 400 patients in the service. Patients in the service are defined as post-transplant patients in follow up + patients on the waiting list + long term ventricular assist devices not on the waiting list.

- NHSE seek action plans from providers to address who are below the national average of patient's reporting that they are not comfortable to raise concerns at all stages of their transplant pathway.