

# Closing thoughts



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# Some thoughts from CTAG Patient Group Chair

| Countries                   | UK    | Scandinavia | Europe | Canada |
|-----------------------------|-------|-------------|--------|--------|
| Population (millions)       | 67.3  | 29.3        | 137.5  | 37.0   |
| Donors                      | 1,397 | 545         | 1,872  | 734    |
| Donation Rate (PMP)         | 20.8  | 18.6        | 13.6   | 19.8   |
| Lung Transplants            | 109   | 127         | 612    | 352    |
| Utilisation Rate            | 7.8%  | 23.3%       | 32.8%  | 48.0%  |
| Lung Transplant Rates (PMP) | 1.62  | 4.33        | 4.45   | 9.52   |

## Summary

As can be seen the UK has world leading organ donation rates.

This, however, is not translating into lung transplants with the UK being by far the worst performer in both utilisation and lung transplant rates.

It should also be noted that the UK post lung transplant outcomes are unfavourable compared to other countries.

# Some thoughts from CTAG Patient Group Chair

- The latest published post lung transplant registration outcomes make sobering reading (NHSBT Cardiothoracic Transplant 2021/22 Annual Report, Section 9.3, pages 75-76)
- 31% of routine patients have died or been removed at 3 years, against a transplant rate of 45%.
- Centre X post registration outcomes are significantly better (8 times more likely to be transplanted than died or removed) and reveal a large access disparity for patients across the country
- The CTPG Chair believes patients deserve to be presented with much improved, up to date access information.
- The NHSBT Risk Communication Tool is a useful tool, but use is sporadic.
- Use should be mandatory for each registration
- NHSBT must ensure the model is regularly updated so patients can make informed decisions.

# Some thoughts from CTAG Patient Group Chair

- Organ transplant dashboard is on the agenda for the lung summit.
- The CTAG PG Chair would strongly support the production of a monthly rolling lung transplant performance dashboard.
- This should be at centre and UK level, set targets and include metrics such as:
  - transplant numbers
  - waiting times
  - waiting list outcomes
  - utilisation rates
  - decline rates
  - decline donor lungs audit results.

# Have we achieved 3 big wins?

- Changes in the allocation system
- Embracing readily available technology
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# Next steps

- Collate all feedback and views from the summit
- Prepare a report based on these
- Circulate this widely for discussion
- Establish short-term working groups to deliver the agreed improvements

*Thank you!*

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