



Royal Papworth Hospital
NHS Foundation Trust

Donor choices in lung transplantation

Patient's guide and
consent form

Lung transplantation is a treatment option for carefully selected patients with advanced lung disease. However, there is a critical shortage of organ donors in the United Kingdom. At three years after being placed on the lung transplant waiting list, 47% of patients have been matched to a suitable donor to undergo lung transplantation. Unfortunately, over the same period, around 30% patients who are listed for a lung transplant die, or need to be removed from the waiting list, before they have the opportunity of receiving a transplant¹.

There are many ways in which we are trying to increase the pool of potential donors for lung transplantation. It is important to understand that every potential donor undergoes thorough assessment by an experienced team and every donor organ has to satisfy stringent criteria before it is accepted for transplantation. Despite this, the function of lungs after they have been transplanted is not completely predictable and there is always a risk of serious complications that may be life-changing or fatal.

We would like to highlight six types of potential organ donor. We believe that you may benefit from receiving a lung transplant from any of these types of donor. However, it is your choice whether you would want to receive a transplant from these types of donor. We need to record your choices in advance, so that we can act in accordance with your choices when donor organs become available.

1. Organs from a donor who is a current smoker or recent ex-smoker

We are frequently offered lungs from donors who are current or previous smokers. Finding out the extent of a donor's smoking history can sometimes be difficult but we generally consider cigarette use equivalent to one pack of cigarettes per day for 20 years to be significant.

International data demonstrates marginally lower 12 month survival and 5 year survival in patients receiving organs from a smoker (survival at 12 months is 3% lower and survival at 5 years is 1.5% lower with smoking donors)². The development of smoking-related lung cancer in transplanted lungs is rare and the risk of transmission of a cancer to a recipient in the UK from a donor not

previously known to have a cancer is around 1 in 2,000³.

The potential effect on post-transplant survival associated with accepting organs from a smoker should be balanced against the significant risk that you might die whilst waiting for a transplant or become too sick for a transplant if you decline donors from this group. Ultimately, around 40% of lung transplants performed in the UK come from donors with a history of smoking and declining such lungs may limit your chance of a transplant¹.

2. Organs from a donor with a current or previous cancer which has a low risk of transmission

We may be offered lungs from a donor with a localised cancer (e.g. brain, thyroid, skin or prostate cancer) where the risk of transmission is believed to be less than 2%³. We may also be offered lungs from a donor who has received successful curative treatment for a curable cancer many years ago. We consider these lungs to be acceptable for transplantation. The small risk of inadvertent cancer transmission associated with accepting such organs should be balanced against the significant risk that you might die whilst waiting for a transplant or become too sick for a transplant if you decline donors from this group. Ultimately, fewer than 5% of the lung transplants performed in the UK come from donors with a history of tumour¹.

3. Organs from a donor who is over 60 years of age

Most lung transplants in the UK are from donors between the ages of 30 and 60 years¹. We may be offered organs from donors who are over the age of 60 years. Research has not yet established an upper limit for a safe 'older donor age'. International data demonstrates marginally better 12 month survival with younger donors, but for those patients surviving beyond 12 months, donor age does not affect longer term survival².

We consider that donor age alone should not be a criteria to reject donor lungs as donor lungs from never smokers can be of better quality than the lungs from smokers of a younger age. All donor organs are assessed

thoroughly for suitability and will only be offered to you if your potential survival benefit exceeds the risks associated with an older donor.

4. Organs from a donor who has no detectable active infection but has a very small chance of carrying a transmittable infection (often due to lifestyle)

All organ donors are screened for active viral infections including HIV, Hepatitis B and Hepatitis C. If these screening tests are positive, then organs would not normally be used. There is a small risk that screening tests may miss recent infection. This can happen if the donor has taken intravenous drugs or participated in high-risk sexual behaviour in the last few days or weeks of their life. In practice, the risk of infection from such donors is very small, between 1 in 5,000 and 1 in 10,000⁴. Effective treatments are now available for these viruses in the event that transmission does occur.

We consider lungs from a donor who has no detectable active infection but has a very small chance of carrying a transmittable infection to be acceptable for transplantation. For a carefully selected group of patients, we may decide to use organs from donors with specific active treatable infections such as Hepatitis C. The transplant team will discuss this with you separately if we think you would be suitable.

5. Organs from a donor following circulatory-determined death (DCD)

Organ donation may occur after brainstem determined (DBD) or circulatory-determined (DCD) death. Potential DCD donors are individuals with a severe medical condition who are being kept alive by artificial means. These patients are not brain dead but they have no chance of recovery. The decision to turn off life support machines and proceed to organ donation is made by the relatives, doctors and nurses caring for the patient.

Organ donation after circulatory-determined death has been accepted practice since the early years of lung transplantation. Since criteria have been established for diagnosing brain stem death, DBD donation has become the more common approach;

however, DCD lung transplantation accounts for approximately 20% of the procedures performed in the UK¹. Survival with lungs from DCD donors is equivalent to that with DBD donors¹.

6. Ex-Vivo Lung Perfusion (EVLP)

Many donor organs deteriorate in the donor prior to transplantation. Ex-vivo lung perfusion (EVLP) is a technique that has been developed to assess, treat and repair donor lungs which may otherwise be discarded due to concerns about quality. As such, EVLP has the potential to significantly increase donor lung availability through the reconditioning of "marginal" organs⁶.

The donor is transferred to an operating room where the lungs are removed and placed into a machine which pumps oxygenated blood into the lungs and allows them to be ventilated at body temperature. At present, we use the TransMedics Organ Care System (OCS) for machine perfusion but other systems may be used in future. Lungs that are suitable for transplantation are transported back to Royal Papworth Hospital with machine perfusion. Only if the function is then deemed acceptable are the lungs then used for transplantation.

International studies suggest that the recipients of EVLP donor lungs have comparable short term and 10 year survival outcomes to conventional donor lung recipients⁶⁻⁸.

Please affix patient label or complete details below.

Full name:

Hospital number:

NHS number:

DOB:

Consent 024

Donor choices in lung transplantation

This form should be completed before going on the list for lung transplantation and reviewed on a regular basis, particularly after any change in your condition.

Before filling in this form, please read the accompanying information. It is important to remember that refusing to accept organs from certain categories of donor will reduce your chance of receiving a lung transplant. Your decision can be changed at any time without affecting your care in any way. We would recommend telling your family or next of kin.

Please choose from the following options:

- ☐ I have read and understand the information given to me in PI 105 Donor choices in lung transplantation.
- ☐ I understand that limiting my selection of donor organs may reduce my opportunity of receiving a lung transplant.
- ☐ I understand that I can change my decision at any time.
- ☐ I would accept organs from a donor that the transplant team considers acceptable for use.

Alternatively, please indicate below the categories of donor from whom you would **NOT** be willing to accept organs:

- ☐ Organs from a donor who is a current smoker or recent ex-smoker
- ☐ Organs from a donor with a current or previous cancer which has a low risk of transmission
- ☐ Organs from a donor who is over 60 years of age
- ☐ Organs from a donor who has no detectable active infection but has a very small chance of carrying a transmittable infection (often due to lifestyle)
- ☐ Organs from a donor following circulatory-determined death (DCD)
- ☐ Ex-Vivo Lung Perfusion (EVLP)

Patient

Patient signature:

Date:

Name (PRINT):

A witness should sign below if the patient is unable to sign but has indicated his or her consent. Young people/children may also like a parent to sign here (see consent policy).

Signed:

Date:

Name (PRINT):

Statement of interpreter (where appropriate).

I have interpreted the information above to the patient to the best of my ability and in a way which I believe he/she can understand.

Signed:

Date:

Name (PRINT):

How do I record my preferences?

Each of these options needs to be considered carefully. It is important to remember that advanced lung disease is a life-threatening illness and is likely to be the greatest risk that you face. We believe that you may benefit from receiving a lung transplant from any of these categories of donor. Declining one of these donor groups will reduce the chances that you are matched to donor organs. However, it is your choice and we will respect your decision. You may also change your mind about any of your decision at any time by letting us know. If you feel uncomfortable with any of these options, then please discuss your concerns with the transplant team. Likewise if there is anything you are unsure about or wish for further clarification then please do call the transplant team.

Contact details

If you would like to speak to a member of the team, please call 01223 638007.

References

1. NHSBT Annual Report on Cardiothoracic Organ Transplantation - report for 2019/2020, published August 2020. (Web link, accessed 01 Apr 2021: <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/19874/nhsbt-annual-report-on-cardiothoracic-organ-transplantation-201920.pdf>)
2. Chambers DC, Zuckermann A, Cherikh WS, et al. The International Thoracic Organ Transplant Registry of the International Society for Heart and Lung Transplantation: 37th adult lung transplantation report - 2020; focus on deceased donor characteristics. *J Heart Lung Transplant*. 2020 Oct;39(10):1016-1027.
3. SaBTO Independent Report - Transplantation of organs from deceased donors with cancer or a history of cancer, published April 2014, updated December 2020. (Web link, accessed 01 Apr 2021: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/948068/transplantation_of_organ_from_deceased_donors_with_cancer_or_a_history_of_cancer-revised_FINAL44266_JNcw_cw.pdf)
4. Halpern S, Shaked A, Hasz R, et al. Informing candidates for solid organ transplantation about donor risk factors. *New Engl J Med* 2008;358:2832-7.
5. Krutsinger D, Reed RM, Blevins A, et al. Lung transplantation from donation after cardiocirculatory death: a systematic review and meta analysis. *J Heart Lung Transplant* 2015;34:675.
6. Loo G, Warnecke G, Villavicencio MA, et al. Portable normothermic ex-vivo lung perfusion, ventilation, and functional assessment with the Organ Care System on donor lung use for transplantation from extended-criteria donors (EXPAND): a single-arm, pivotal trial. *Lancet Respir Med*. 2019 Nov;7(11):975-984.
7. Jawitz OK, Raman V, Becerra D, et al. Lung Transplantation After Ex Vivo Lung Perfusion: Early Outcomes From a US National Registry. *Ann Surg*. 2020 Jul 24. Epub ahead of print.
8. Divithotawela C, Cypel M, Martinu T, et al. Long-term Outcomes of Lung Transplant With Ex Vivo Lung Perfusion. *JAMA Surg*. 2019;154(12):1143–1150.

Royal Papworth Hospital NHS Foundation Trust

Papworth Road

Cambridge Biomedical Campus

Cambridge

CB2 0AY

Tel: 01223 638000

www.royalpapworth.nhs.uk

A member of Cambridge University Health Partners

Author ID: Lung Transplant Consultants
Department: Transplant Unit
Reprinted: July 2021
Review due: July 2023
Version: 2.1
Leaflet number: PI 105

© Royal Papworth Hospital NHS Foundation Trust

Large print copies and
alternative language
versions of this leaflet
can be made available
on request.