



Organ Transplant Aftercare and Support: Survey

Participant Information Sheet

Opens: 25 September 2023

Closes: 29 December 2023

Overview

In March 2021, the Scottish Government published its [Donation and Transplantation Plan for Scotland: 2021-2026](#).

The Plan was developed with members of the Scottish Donation and Transplant Group (SDTG) and sets out recommendations in seven key priority areas. One of the key priorities is Transplant Recipient Support and Aftercare.

This survey has been developed by a Working Group of the SDTG and aims to capture an up-to-date picture of patients' views on transplant services in Scotland.

NHS National Services Division (NSD) commissions transplant services for people who live in Scotland. In 2020, a patient survey conducted by NSD identified a number of areas where the patient's experience could be improved. These include communication between transplant units, local specialists, GPs and patients; the availability of information and advice; and access to emotional and psychological support for patients and their families.

During the pandemic, many services adopted new ways of seeing patients, offering remote monitoring and remote/online consultations. While this reduced the need to travel to hospital appointments, it is important to explore the impact of these changes on transplant patients.

Why your views matter

Patient feedback is essential to ensure that transplant services are meeting the needs of their patients.

We are undertaking this survey to seek the views of Scottish recipients of a solid organ transplant. This includes those who have had one of the following organ transplants:

- Heart
- Lung
- Kidney
- Liver
- Pancreas
- Simultaneous pancreas-kidney
- Simultaneous islet-kidney
- Islet cells

We want to explore patients' experiences of using transplant services and whether there are any areas for improvement.

Therefore please only complete this survey if you live in Scotland, are aged 16 or over, and have had an organ transplant from either a deceased or living donor. Or you can also complete it on behalf of someone (such as a family member) who has had a transplant, but is not able to complete the survey themselves.

We will produce a report outlining the findings from the survey which will be shared with the Scottish Donation and Transplant Group and with Transplant Units. We do not intend to include any individual survey responses in the report; particular comments or suggestions may be included, but this will be done in a way that ensures no individuals can be identified from their comments.

The report will also be published on the Scottish Donation and Transplant Group page on the Scottish Government website <https://www.gov.scot/groups/scottish-donation-and-transplant-group>.

Completing the survey

The survey will take approximately **10 - 15 minutes** to complete.

Please answer the questions based on your own experience, or if you are answering on someone else's behalf, their experience of having an organ transplant.

If you have received more than one solid organ transplant, please complete one survey for each transplant experience.

The survey has six sections and 31 questions. **You do not need to answer all the questions if you do not want to.**

Section 1 – About you

This section is to gather information about patients' age, sex, ethnic origin, which NHS Board area they live, what organ(s) they have had transplanted, etc. We are collecting this information as we want to identify how we can deliver services which are more suited to the individual.

Section 2 - Communication, education and advice

This section is to explore patients' experiences of receiving information about their transplant and knowing how to get advice. It is important to have good communication between patients, transplant teams, local specialists and GPs.

Section 3 - Emotional/psychological support

This section is to explore what emotional support transplant recipients and their partners/family members have needed, what they have received, what has been most helpful and what type of support should be available in the future.

It is understandable that you may find thinking about aspects of emotional support difficult. If you feel that you need to speak to a professional please contact:

Organ Transplanted	Transplant Co-ordinator
<ul style="list-style-type: none"> • Kidney Transplant 	Renal Transplant Coordinators Edinburgh Transplant Unit 0131 242 1728 <u>loth.renaltxcoords@nhslothian.scot.nhs.uk</u>
<ul style="list-style-type: none"> • Pancreas Transplant • Simultaneous Pancreas-kidney 	Mel Phillips Transplant Coordinator Edinburgh Transplant Unit 0131 242 2894 07872420966 <u>melanie.b.phillips@nhslothian.scot.nhs.uk</u>
<ul style="list-style-type: none"> • Liver Transplant 	Liver Transplant Coordinators Edinburgh Transplant Unit 0131 242 1721 <u>SLTU@nhslothian.scot.nhs.uk</u>
<ul style="list-style-type: none"> • Islet cell Transplant • Simultaneous Islet-kidney 	Kirsty Duncan Islet Cell Transplant Coordinator Edinburgh Transplant Unit 0131 242 1730 <u>kirsty.duncan@nhslothian.scot.nhs.uk</u>
<ul style="list-style-type: none"> • Heart Transplant 	Golden Jubilee National Hospital <u>GJNH.Snahfsspecialistnurses@GJNH.scot.nhs.uk</u>
<ul style="list-style-type: none"> • Lung Transplant 	Freeman Hospital Newcastle <u>nuth.tccu2011@nhs.net</u>

Section 4 - Transplant centres and travel

This section explores patients' experiences of travelling to their transplant centre.

Section 5 - Transplant aftercare

The Covid-19 pandemic has changed the way services are delivered, with many transplant centres offering video consultation such as 'Near Me' or a telephone consultation as an alternative to a face-to-face appointment at a clinic. Remote consultations can improve access to services for transplant patients and reduce the need for travel to appointments.

'Near Me' is a confidential and secure service which allows patients to attend their pre-arranged appointment using a video call.

This section explores the impact of these changes on transplant patients and considers the best way to deliver services in the future.

Section 6 - Remote monitoring

Transplant patients need to be monitored regularly, including blood tests to check on the functioning of organs and test the level of immunosuppressant medication.

This section explores patients' preferences in relation to post-transplant monitoring

Your rights

- You do not have to take part in this survey
- You can end the survey at any time, and you do not have to give a reason. We will keep what you tell us private
- You can ask to see any information about you that we have kept
- You can ask us to update or delete what we know about you and what you said in the survey, even after the survey has ended
- No one will be able to work out who you are from any reports we may publish
- We will use what you tell us for research and recommendations for improvements to services only

Responding to this survey

We are inviting responses to this survey by **29 December 2023**.

We ask that you respond to this survey using the Scottish Government's online survey tool, which is called Citizen Space at <https://consult.gov.scot/population-health/organ-transplant-recipient-support-and-aftercare>

You can save and return to your responses while the survey is still open.

If you are unable to respond using Citizens Space, you can request a paper copy of the survey and a pre-paid envelope by emailing organ_donation_scotland@gov.scot or by contacting your transplant unit.

Please also email organ_donation_scotland@gov.scot or contact your transplant unit if you require a copy of the survey in an alternative format or another language.

Personal data

To find out how we handle your personal data, please see our [privacy policy](#).

How your data will be stored

All response data (excluding personal data) is kept indefinitely for our records. However the Scottish Government's data management policy requires that your response is kept for no longer than three years and it is expected that individual responses will be securely deleted so that any personal information is not kept any longer than is necessary.

Thank you for taking the time to complete this survey.