

# **Support and Care after an Organ Transplant**

## **Patient Survey**

**Easy Read Version**




**September 2023**


# **Support and Care after an Organ Transplant**

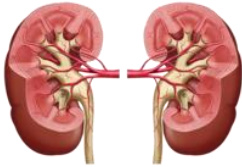
## **Patient Survey**

### **Easy Read Version**



 <p>ORGAN DONATION <b>SCOTLAND</b></p> <p>Scottish Government</p>	<p>In March 2021 the Scottish Government published the Donation and Transplant Plan for Scotland: 2021 – 2026.</p>
 <p>AN ORGAN DONATION STRATEGY FOR SCOTLAND</p> <p>Scottish Transplant Group Report</p> <p>JUNE 2022</p>	<p>Members of the <b>Scottish Donation and Transplant Group (STDG)</b> decided on <b>7</b> important areas to be worked on.</p> <p>These were called <b>key priorities</b>.</p>
	<p>One of those is about the support and aftercare people get after getting a transplant.</p>

	<p>This survey is so we have an up to date picture of what people think about transplant services in Scotland.</p>
---	--

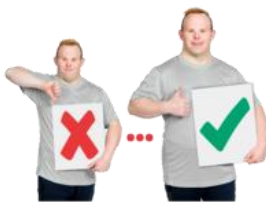


The survey will look at views from transplant patients who have had one or more of the following:






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



We want to hear what it was like for transplant patients.



We want to know what we could make better for transplant patients.

	<p>You should complete this survey if:</p> <ul style="list-style-type: none"> <li>• you are over <b>16</b></li> <li>• you live in <b>Scotland</b></li> <li>• you <b>have had an organ transplant</b> from someone either alive or dead</li> </ul>
	<p>If you are not able to complete the survey yourself, someone else can do it for you.</p> <p>This could be a family member.</p>
	<p>We will use the information we get from the surveys to write a report.</p>
	<p>The information will be shared with the <b>STDG</b> and Transplant Units.</p>
	<p>We will not include any individual comments from anyone.</p> <p>No one will be able to be identified from any information we share in the report.</p>



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 has **6 sections** and **31 questions**.

You **do not** need to answer all the questions if you do not want to.



The survey should take you about 15 minutes to complete.

Please answer the questions based on what your experience was like.



If you are answering for someone else, please answer based on their experience.



The survey will be open from the **25<sup>th</sup> September 2023 to the 29<sup>th</sup> December 2023**

All completed surveys should be sent to us by the **29<sup>th</sup> December 2023**.



## Privacy Notice





We are the Organ and Tissue Donation and Transplantation Policy Team.



Our head office is at **St Andrew's House, 2 Regent Road, Edinburgh EH1 3DG.**

	<p>We are asking people who have had solid organ transplants to tell us about:</p> <ul style="list-style-type: none"> <li>• their aftercare</li> <li>• their support</li> </ul>
	<p>This is important for us.</p> <p>It helps us to make sure we are meeting the needs of patients.</p> <p>It will help us to improve our patient services.</p>

	<p>The survey is <b>optional</b>.</p> <p><b>Optional</b> means you do not have to answer all the questions if you do not want to.</p>
	<p>We follow the law on how to protect your information.</p> <p>It is called the <b>General Data Protection regulation (GDPR)</b></p>





We will not use information that would identify who you are.

This is things like:

- your name
- your address
- your email address



We will look closely at the answers you give us.

We will write a report on the things you tell us.



The Scottish Government rules on keeping information is that it should be kept for **3 years**.

We will look at your personal information after **1 year**.

We will decide if it can be safely deleted.

Any other information which does not identify you will be kept for as long as we need it.



Your information is kept secure and private.

## Your rights



You have the right to see any information we have about you.



You can see your information by getting a **Subject Access Request (SAR)**

You can ask for this here:

<https://www.gov.scot/publications/subject-access-request-form>.



If you think the information we have about you is wrong or not complete you can contact [Organ\\_donation\\_scotland@gov.scot](mailto:Organ_donation_scotland@gov.scot)

We will update our records with information you give us.

# Complaints



If you are not happy with how we use your information you can make a complaint.



You can do this by contacting:

[DataProtectionOfficer@gov.scot](mailto:DataProtectionOfficer@gov.scot)

Or you can write to:



**Data Protection Officer**  
**Victoria Quay**  
**Commercial Street**  
**Edinburgh, EH6 6QQ**



If you think we have not dealt with your complaint well you can write to the  
**Information Commissioner's Office  
(ICO): The Information Commissioner  
Wycliffe House  
Water Lane Wilmslow  
Cheshire, SK9 5AF**

**Tel: 08456 30 60 60**

Or email:

<https://ico.org.uk/concerns/handling/>

## What words mean

You will see some words in this document in **blue**. The first time you see a word it will be **bold**. This means it is a new word. This list will tell you what the word means.




© Crown copyright 2023

**OGL**

This publication is licensed under the terms of the Open Government Licence v3.0 except where otherwise stated. To view this licence, visit [nationalarchives.gov.uk/doc/open-government-licence/version/3](https://nationalarchives.gov.uk/doc/open-government-licence/version/3) or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU, or email: [psi@nationalarchives.gsi.gov.uk](mailto:psi@nationalarchives.gsi.gov.uk).

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

This publication is available at [www.gov.scot](http://www.gov.scot)

Any enquiries regarding this publication should be sent to us at

The Scottish Government  
St Andrew's House  
Edinburgh  
EH1 3DG

ISBN: 978-1-83521-366-7 (web only)

Published by The Scottish Government, September 2023

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA  
PPDAS1344462 (09/23)

W W W . g o v . s c o t