Documentation submitted by NHS Blood and Transplant to Professor Sir Gordon Duff's Independent Review

Miscellaneous documents

ODR143 Leaflet 'Thank you for joining the NHS Organ Donor Register'
NHS Organ Donor Register National Contact Center User Guide



The NHS Organ Donor Register is a confidential, computerised database which records the wishes of those people who have decided that they want to leave a legacy of life for others after their death. The Register is maintained by NHS Blood and Transplant and details are only made available to authorised NHS hospital staff.

Thank you for showing your support for organ donation



If you have any questions about organ donation, please ring 0300 123 23 23 at any time or go to

www.organdonation.nhs.uk

Thank you for joining the NHS Organ Donor Register



Emily Thackray was born with cystic fibrosis, a progressive disease causing chronic respiratory and digestive problems.

Thanks to a life-saving double lung transplant made possible by the generosity of a donor, she is now living the normal life she had dreamt of for so long.

"Words cannot express my gratitude to my donor and their family; I was determined

to live, but all my hopes and dreams depended on their decision. They have saved my life," says Emily.



Thank you for making the commitment to help others live after your death

Many lives could be saved or transformed through your generosity.

Your details are included on the letter you received with this leaflet. Please check them to make sure they are correct. If you wish to make any changes, please ring 0300 123 23 23 or visit our website at www.organdonation.nhs.uk.



Daljit Toor, was an apparently fit 23 year-old motor mechanic and martial arts instructor, when he discovered his kidneys were failing and his decade-long wait for a donated organ began.

He said: "My new life has been made possible only because someone donated a kidney and I feel immensely grateful to them and their family."

Please let those closest to you know your wishes about organ donation

The enclosed card demonstrates your commitment to organ donation and that you have joined the NHS Organ Donor Register. You don't need to carry this card as your details are recorded on the Register. It is important you let those closest to you know your wishes about organ donation so that they can be respected after your death.



Gaynor Taylor knows more than most the pain of losing a loved one.

In 2004, her son Richard died after being critically injured in a skating accident. Less than two years later, her husband John died from a heart attack. Both

had joined the NHS Organ Donor Register, wanting to help others live by donating their organs when they died.

Thanks to Richard's gift, six people were given a second chance, while John, who was able to donate his tissue, also helped others have a brighter future. Gaynor, says she is eternally proud of both of them.

"It's such a devastating time when you lose someone, but I did find it comforting, as did John when Richard died, knowing that they were helping others live."

"It fills me with so much strength knowing that my son and husband's lives have not been wasted."





NHS Organ Donor Register National Contact Center User Guide

ODR application version 2.3

National Contact Centre Staff

Teleperformance Service Desk:

ODT - Organ Donation Register Team: 01179 9757553



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INTRODUCTION

As one of the three arms of NHS Blood and Transplant, Organ Donation and Transplantation's key role is to ensure that organs donated for transplant are matched and allocated to patients in a fair and unbiased way. Matching, particularly in the case of kidneys, is so important that donation and allocation needs to be organised nationally.

In providing support to transplantation services across the UK, everything ODT does has an impact on the quality of service delivered to individual patients. One of ODT's specific responsibilities includes maintaining the national NHS Organ Donor Register (ODR), which is maintained by the Organ Donation Register Team at ODT.

The Organ Donor Register (ODR) contains basic personal information of people from the UK who have registered themselves to donate their organs. The ODR can register potential donors, update information, check validations and for duplicate entries and run reports.

ODR and National Contact Centre personnel

With the introduction of the ODR for National Contact Centre (NCC) personnel, NCC will be able to:

- 1. Update registered donor details directly through the ODR, when required
- 2. Initiate the process for sending confirmation letters to be sent to the registrant confirming their current details and donation preferences

All other processes within the NCC related to ODT will remain the same. This includes:

- 3. Registering new donors on the ODR
- 4. Withdrawing donors from the ODR

For further details on the above points 3 and 4 please contact the ODR team at ODT.

Using this guide

This guide is aimed at National Contact Centre personnel who, from an ODT perspective, are external users of the Organ Donation Register. National Contact Centre personnel that have access to ODR will all be assigned the same user role within the ODR application.

National Contact Centre personnel will be able to update registered donors details through the ODR, when required.

Formatting

The following icons are used to indicate actions or information within this guide:

An action that you perform in ODR

The results of the action you performed

(i) Information or warning

CONNECTING TO ODR

Setting up your account

Your username and password will have been provided to you by Teleperformance, on commencing this role at NCC. Your username and password will be unique for your access.

An example username is user 01. Your password will be at least 8 characters long, must contain at least 1 letter and 1 number.

Log onto the internet

You can access the ODR from an internet-enabled computer with Microsoft Internet Explorer version 6 or 7 installed that is over a secure connection to the NHSBT network.

Checking your internet Explorer version

- Start Internet Explorer
- Click on the Help menu
- Select About Internet Explorer
 - The version details will be displayed



Logging onto ODR

- Connect to Tempest homepage
- Click on the Organ Donor Register link

The login window will be displayed

- Enter your User name
- Enter your Password
- Your password is case sensitive
- Click OK

The ODR window will open displaying your default Home Page.



Forgotten Password

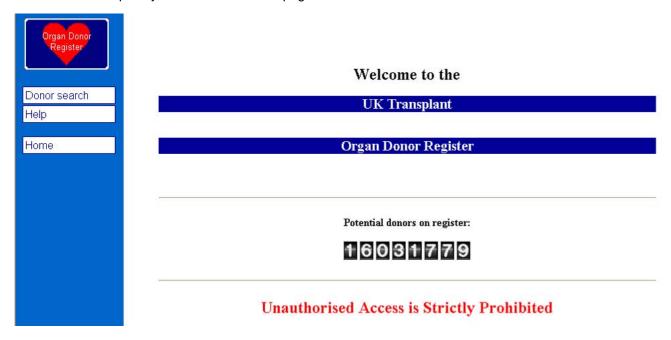
If you have forgotten your password, please contact the Teleperformance Service Desk.

Expired Password

Your password will expire after 90 days, where you will be prompted to change your password.

HOMEPAGE LAYOUT

Below is an example layout of the NCC homepage.



HOME	Link to the Homepage. Visible on all pages on the application
HELP	How To Guides

GENERAL FUNCTIONALITY

Below is a selection of general functionalities, best practices and useful tips/ links within the ODR system.

Quick Keys

Ctrl+F	Find	Ctrl+P	Print
Ctrl+C	Сору	Ctrl+V	Paste

Auto Tab

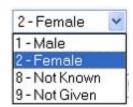
Auto Tab function is available for all date fields, where on entering two digits for the day and month will automatically move your curser to the next field.

For entering or selecting all other data, you can click the TAB key on your keyboard to move your cursor to the next field.

Pick Lists

These display when you are entering data and are denoted by a down arrow next to the field.

- Click on the down arrow and select from the list of options
- (i) When the field is highlighted (in blue) you can press the up or down keys to select the option



Free Text

These are fields where information is typed into the section.

Data Entry Best Practice

When completing the screens in ODR, please bear the following points in mind:

- Avoid leaving fields blank, if the answer is No or Unknown, select these options
- Avoid using Other rather than selecting an option from a pick list
- All years are entered using a 4 digit year e.g. 2009
- Make sure you put the correct text descriptions in the correct boxes

All the data that you enter goes into a database from which statistics are generated. If data is entered incorrectly or is incomplete, then the reports generated become meaningless.

Useful links

<u>www.organdonation.nhs.uk</u> Link to organ donation homepage where donors can register online.

www.nhsbt.nhs.uk Link to NHSBT homepage

DONOR SEARCH

The donor search facility allows you to search for donors who are registered on the ODR.

- Click on Donor search in the menu bar
 - 1 The Search Donor Register will display
 - Enter your search criteria (see below for best practices for a donor search).
 - Click Search
 - The search criteria is NOT case sensitive
 - (i) The search criteria will NOT allow special characters (i.e. -, ')

To remove all the search criteria entered:

Click on Reset

Search Donor Register

Please enter sea	arch criteria
Surname	
Forename	
Sex	
Date of birth	
Postcode	
Address line 1	
Address line 2	
Register number	
NHS number	
Search Reset]

Best Practices for a Donor Search

Entering as many criteria as possible will narrow the search. Using wildcards can decrease false negative returns.

Wildcard Searches

Information is likely to have been entered in different formats within the ODR, for example only an initial may have been entered for a forename and therefore will not return the registered donor if the full forename is used in the forename search criteria, hence returning false negatives.

To reduce the return of false negatives, a wildcard search can be used.

To use a wildcard search, enter the minimal information for that followed by the wildcard symbol - %. For example enter the first initial (M) for the forename (Mary), followed by % - (M%)

The wildcard search can be used in the following search fields:

- Surname
- Forename
- Postcode
- Address Line 1 and 2
- NHS Number
- Register number

Searching Options

To return the correct search result in a timely manner, it is recommended that the following options for searching for a donor are followed in the order specified below.

First Donor Search Option

Register number (This should return only one matched result)

Second Donor Search Option

- Full Surname
- First Letter of the Forename with wildcard (see section below for wildcard details)
- Date of Birth

Third Donor Search Option

- Full ID number, either NHS number or DVLA number
 - NHS number may not always be recorded; in these cases no result will be returned.

Fourth Donor Search Option

- Postcode (Does not require wildcard as the field will find a full postcode whether the space is added in the middle or not)
 - (i) e.g. Postcode BS16 6HQ can be retrieved by entering either of the following BS16 6HQ or BS166HQ

Search Donor Register

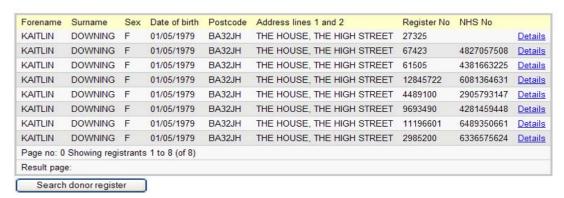
Surname	Cole	
Forename	C%	
Sex		
Date of birth	11 05 1953	
Postcode		
Address line 1		
Address line 2		
Register number		
NHS number		

Search criteria	Description	Guide for entering criteria
Surname	Last name of the donor	Enter this as a minimum search criterion; exception is with a full ID number. Use a wildcard for surnames which contain special characters, e.g. double barrelled names.
Forename	First name of the donor	This may be recorded in different formats i.e. first letter only.
Sex	Gender of the donor	This maybe recorded incorrectly.
Date of Birth	Date of Birth of the donor	Date of Birth must be entered with 2 digits for the day and month, and 4 digits for the year.
Postcode	Postcode of the donor	There is no need to add a wildcard in place of the space in the postcode. The system will check postcodes regardless of the format entered. E.G. Entering BS34 8RR will retrieve BS348RR or BS34 8RR.
Address line 1	Address of the donor	
Address line 2	Address of the donor	
Register Number	Register number of the donor	This number is included in correspondence with the registered donors. All registrants have a registration number.
NHS Number	NHS number of the donor	This may not be recorded in all registered donors.

DONOR SEARCH RESULTS

After the search has been performed any matching registrants will be displayed on the "Donor Search Results" page.

Donor Search Results



- The donors on the "Donor Search Results" page will display all 8 search criteria: Forename, Surname, Sex, Date of Birth, Postcode, Address line 1 and line 2, Register number and NHS number
- The record results will be ordered alphabetically (Surname, Forename)
- Up to 100 matching results will be displayed on each page
- · There may be more than one page of donors

To view additional pages of donors from the donor search results:

Click on the "Result page" number

To amend the donor search:

- Click on Search donor register
- i This will display a blank "Search Donor Register" page

To view donor registration details:

- Click on the Details link for that registrant
- (i) The donor details and donation preferences will be displayed.

To go back to the list of donor search results:



If no donors are found with the search criteria supplied, then the ODR will display the no matched results.

To amend the donor search:



i This will display the "Search Donor Register" page

Donor Search Results



Identifying Duplicates

Although there are preventative methods in place at ODT to avoid possible duplicate registrations of donors on the ODR, this can not always be avoided. All possible duplicates need to be recorded and reported to ODT for analysis.

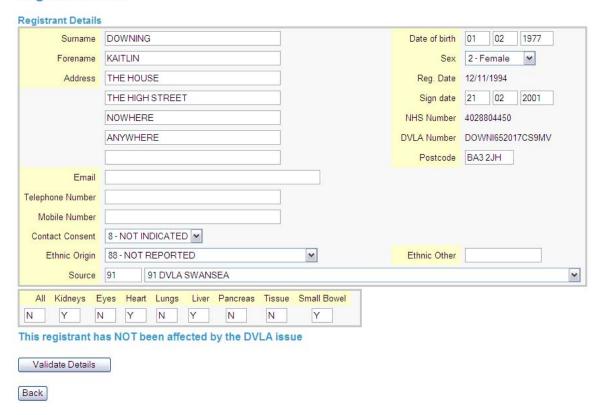
If any amendments are required, update the record with the most current Sign Date.

AMENDING AND CONFIRMING DONOR DETAILS

The 'Registrant Details' page may vary depending on whether there is or is not a record of incorrect or indeterminable organ preference.

Below is an example where there is **NO record of incorrect or indeterminable organ preferences (**this is indicated by the comment 'This registrant has not been affected by the DVLA issue' at the bottom of the screen).

Registrant 13359



To amend registrant details:

- Select the field to be amended

 Surname

 Enter new data in the appropriate field
- Click on Validate Details

 "Validate details" will check for an
 - (i) "Validate details" will check for any errors within the database

Amending Registrants Donation Preferences

There are 9 organs or tissues that can be selected for donation preference.

To change the registrants preference:

- Type "Y" or "N" meaning yes or no respectively to note if "ALL" organs for donation is the registrants preference
 - i If Y has been selected, all organ preferences will be updated automatically to display Y in all organ fields

If No has been selected to 'All' organs:

Type "Y" or "N" meaning yes or no respectively to



to...

COLE

Surname

each individual organ donation preference

This is NOT case sensitive

If the registrant details do not need to be amended they will need to be verbally confirmed.

After verbally confirming the registrant details:

Click on Validate Details

When the 'Registrant Details' have been validated with no errors (See "Data Validation") a confirmation page will display. The confirmation page may vary depending on whether there is or is not a record of incorrect or indeterminable organ preference.

Below is an example where there is NO record of incorrect or indeterminable organ preferences

Registrant 13359 Messages Registrant is valid. Please save. Registrant Details Surname DOWNING Date of birth 01 02 1977 Forename KAITLIN 2 - Female Address THE HOUSE Reg. Date 12/11/1994 THE HIGH STREET Sign date 21 02 2001 NOWHERE NHS Number 4028804450 DVLA Number DOWNI652017CS9MV ANYWHERE Postcode BA3 2JH Email Telephone Number Mobile Number Contact Consent 8 - NOT INDICATED 88 - NOT REPORTED ~ Ethnic Other Ethnic Origin 91 91 DVLA SWANSEA Source V Kidneys Eyes Heart Lungs Liver Pancreas Tissue Small Bowel N N N N The registrant will be sent a letter confirming their current details Please uncheck this box if the registrant DOES NOT wish to receive this letter Save Details

The "Registrant is valid" message will be displayed at the top of the 'Registrant Details' page.

Confirmation Letters

A confirmation letter should be sent to the donor each time the registrant confirms or updates their details. The confirmation letter will outline the registrant's details and donation preferences which are stated on the ODR and will be posted to their registered address.

The confirmation letter check box is defaulted to send the letter.

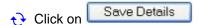
Inform the registrant they will receive a letter confirming their details and organ donation preferences in a confirmation letter

If the registrant would not like to receive the letter:

- Click on the Confirmation letter tick box
- This will remove the tick in the box



To save the amendments:



- This will display a new window, confirming the "this course of action" to save the information
 - Click OK to save
- This will BRIEFLY display the "Registrant saved successfully" message at the top of the donor registration page before the "Search Donor Register" screen is displayed.



Organ Preference Status

There are 5 scenarios which may be encountered if there **IS** a record of incorrect or indeterminable organ preference.

- Scenario 1 Corrected by ODT
- Scenario 2 Unconfirmed
- Scenario 3 Corrected by Registrant
- Scenario 4 Confirmed by Registrant
- Scenario 5 Previously Unknown Corrected by ODT

For these registrants there is an additional field indicating the status of the incorrect or indeterminable organ preference. This field is called 'Organ Preference Status'.

There are two further scenarios which may be encountered if a registrant's organ preferences initially could not be determined by ODT but were subsequently either corrected or confirmed externally (e.g. by the registrant telephoning or another source, data feed etc.) or internally (e.g. after further in-house analysis ODT have proved the preferences to be correct).

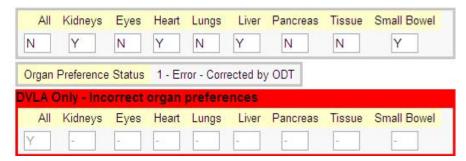
- Scenario 6 Corrected/Confirmed by External Source
- Scenario 7 Previously Unknown Confirmed by ODT

Once again, for these final two statuses, there is an additional field indicating the status of the organ preferences. This field is called 'Organ Preference Status'.

Scenario 1 - Corrected by ODT

The following will appear if the registrant's organ preferences were either incorrect or could not be determined and these have subsequently been corrected by ODT.

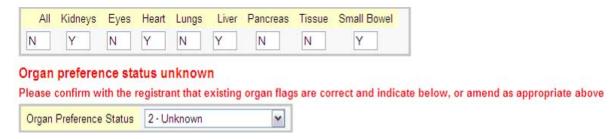
'Organ Preference Status' field indicated the preferences have been corrected by ODT and the previous (incorrect) ODR record of the registrants organ donation preference is highlighted in red, under 'DVLA Only – Incorrect organ preference'. These fields are not editable.



Scenario 2 - Unconfirmed

The following will appear if the registrant's organ preferences could not be determined by ODT and these

have not yet been confirmed or corrected.



If the registrant has unconfirmed organ preferences, update or confirm the registrant's organ donation preference accordingly.

To correct the organ preference:

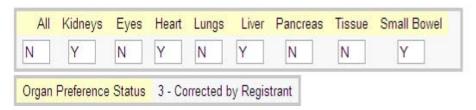
- See section 'Amending Registrants Donation Preferences' to amend the organ preference
- Under Organ Preference Status, Select 'Confirmed by Registrant'
- Click 'Validate details'

If no changes are required, *confirm* the organ preference:

- Under Organ Preference Status, Select 'Confirmed by Registrant'
- Click 'Validate details'

Scenario 3 - Corrected by Registrant

The following will appear if the registrant's organ preferences has been confirmed or corrected by the registrant.



The 'Organ Preference Status' field will not be editable and will display '3 – Corrected by Registrant'.

Scenario 4 - Confirmed by Registrant

The following will appear if the registrant's organ preferences has been confirmed or corrected by the registrant.

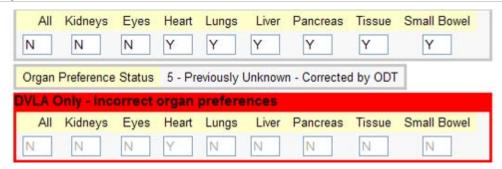


The 'Organ Preference Status' field will not be editable and will display '4 - Confirmed by registrant'.

Scenario 5 - Previously Unknown - Corrected by ODT

The following will appear if the registrant's organ preferences has been confirmed or corrected by the registrant.

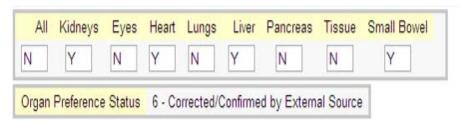
'Organ Preference Status' field indicated the preferences have been corrected by ODT and the previous (incorrect) ODR record of the registrants organ donation preference is highlighted in red, under 'DVLA Only – Incorrect organ preference'. These fields are not editable.



The 'Organ Preference Status' field will not be editable and will display '5 – Previously Unknown – Corrected by ODT'.

Scenario 6 - Corrected/Confirmed by External Source

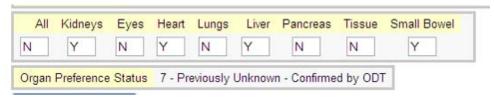
The following will appear if the registrant's organ preferences has been confirmed or corrected by an external source (e.g. by the registrant telephoning or another source, data feed etc.).



The 'Organ Preference Status' field will not be editable and will display '6 – Corrected/Confirmed by External Source.

Scenario 7 - Previously Unknown - Confirmed by ODT

The following will appear if the registrant's organ preferences had previously been unknown but have subsequently been confirmed internally by ODT.



The 'Organ Preference Status' field will not be editable and will display '7 – Previously Unknown – Confirmed by ODT'.

Data Validation

Some data fields are mandatory. If the data from these fields have been removed you will not be allowed to save the data on that screen and an error message will display.

Some data entry has to be within a valid range. This is not indicated on the screen, but if you enter data outside the range, when you try to save, an error message will display.

Message Types

There are three of message:

Type of	Description	Example
message		

Confirmation

Shown in White, indicating successful completion of the task

Registrant saved successfully

Warning Shown in Yellow, indicate less

information. The data is validated

and can be saved

Messages

Messages

Ethnic Origin has been changed to a less accurate value

Registrant is valid. Please save.

Error Shown in red. These are errors

that must be corrected before

you can proceed

Messages

Surname must be at least one character in length

Entry Fields Summary

All the entry field types are outlined below, including their mandatory status and the type of entry that is required for that field.

Entry Field	Description	Status	Entry type
Surname	Donor Surname	Mandatory	Text
Forename	Donor Forename	Mandatory	Text
Address line 1	First line of the donors address	Mandatory	Text
Address line 2	Second line of the donors address	Mandatory	Text
Postcode	Donors Postcode	Not Mandatory	Text
Email	Donor contact email	Not Mandatory	Text
Telephone number	Donor contact number	Not Mandatory	Text
Mobile number	Donor contact mobile number	Not Mandatory	Text
Contact consent	Denotes if the donor minds being contacted	Can not be deleted, can be amended	Dropdown
Ethnic Origin	Donor ethnic origin	Not Mandatory	Dropdown
Ethnic Other	Donor ethnic origin if not available on the "Ethnic Origin" field	Mandatory if an "other" option is selected for "Ethnic Origin"	Text
Source (1 st field)	Number code of the process which collected the current donor data	Mandatory	Text
Source (2 nd field)	Explanation of Source number code	Mandatory	Dropdown
Date of Birth	Donor date of Birth – 3 entry fields correlate to Day, Month in 2 digit format and Year in 4 digit format	Mandatory	Text
Sex	Gender of the donor	Can not be deleted, can be amended	Dropdown
Reg. Date	Date the donor registered to on the ODR	N/A	Not editable
Sign Date	Last date any changes were made to the registrant on the ODR. 3 entry fields correlate to day, month in 2 digit format and year in 4 digit format	Mandatory	Text
NHS Number	Donor NHS number, will only be available if the NHS number has been updated by an automatic system.	N/A	Not editable
DVLA Number	Donor Driver and Vehicle Licensing Agency number, will only be available if the donor registered onto the ODR via the DVLA feed	N/A	Not editable

Entry Field	Description	Status	Entry type
Donation Preference	Shows the organs the donor wishes to donate. If under ALL "Y" is selected all organs can be donated. If under ALL "N" is selected the organs that the donor wishes to donate must be selected.	Mandatory	Text
Organ Preference Status	Indicates the status of registrant records where there is an incorrect or indeterminable organ preference record	Variable	Variable

Approvals

Name	Role	Date Approved
Angille Heintzman	Quality Assurance	13/04/2010
Samantha Bragg	Quality Assurance	13/04/2010

APPENDIX

Below is an outline of the alterations implemented from ODR application from version 1.1 to version 2.0:

Section	Description of NHS ODR Version 2.0 alterations	Reflected on:
Registrant Details page	Skin has been removed as a tissue that can be selection as a donation preference	N/A
Registrant Details page	A comment has been added to identify those registrants who do not have records with incorrect or indeterminable organ preferences	Page 11
Registrant Details page	All registrant details and organ preferences need to be confirmed	Page 12
Registrant Details page	Check box for Confirmation Letters to be sent to the registrant, unless the registrant specifies otherwise.	Page 12

Below is an outline of the alterations implemented from ODR application from version 1.0 to version 1.1:

Section	Description of NHS ODR Version 1.1 alterations	Reflected on:
Donor Search	Two additional search fields have been included (NHS number and DVLA number).	Page 7
Donor Search	'Searching Option 2' has been added to reflect the additional search fields.	Page 8
Donor Search Result page	Three additional points of identification have been included (Address, NHS number and DVLA number).	Page 10
Donor Search Results page	National Contact Centre personnel search results does NOT return deceased registrants.	N/A
Registrant Details page	Three additional screen sections have been created to reflect 'Organ Preference Status' for registrants who may have a record of incorrect or indeterminable organ preference. 1 of these screen sections is visible depending to the registrant's organ preference status.	Page 11-13
Registrant Details page	Registrant withdraw reason is not visible.	N/A
Registrant Details page	'Search donor register' link has been removed.	N/A