

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

## **Patient Survey - Part Two**

**Easy Read Version**

# Support and Care after an Organ Transplant



## Patient Survey



The survey is **optional**. This means you do not need to answer all the questions if you do not want to.

### Section 1

#### About you.



The information we ask for here will help us to make our services more suited to each person.



1.  
What age were you on your last birthday.?

Please write the answer in the box.



2. What sex are you?

Female

Male

Do not want to say



3. Are you trans or do you have a trans past?



No

Yes

Do not want to say

If you want to you can tell us more.

For example:

Non- binary

Trans man

Trans woman



4. What is your ethnic group>

**Scottish**

**Other  
British**

**Irish**

**Gypsy/  
traveller**

**Polish**

**Mixed or  
more than 1  
group**

**Pakistani  
Scottish or  
British  
Pakistani**

**Indian  
Scottish or British  
Indian**

**Bangladeshi  
Scottish or  
British  
Bangladeshi**

**British**

**Chinese  
Scottish or  
British  
Chinese**

**African  
Scottish or  
British African**

**Caribbean  
Scottish or  
British  
Caribbean**

**Black  
Scottish or  
British  
black**

**Arab  
Scottish  
or British  
Arab**

**African  
Scottish or  
British African**

**Other  
origin**

**Do not want  
to say**



If you ticked other please tell us why  
in the box.

5. Which National Health  
Service Board area do you live  
in?

**NHS  
Ayrshire  
and Arran**

**NHS  
Borders**

**NHS  
Dumfries  
and  
Galloway**

**NHS  
Fife**

**NHS  
Forth  
Valley**

**NHS  
Grampian**

**NHS Greater  
Glasgow  
and Clyde**

**NHS  
Highland**

**NHS  
Lanarkshire**

**NHS  
Lothian**

**NHS  
Orkney**

**NHS  
Shetland**

**NHS  
Tayside**

**NHS  
Western  
Isles**

6. Which organ(s) have you had transplanted?

If you have had more than 1, please complete a survey for each transplant.

Heart

Lung

Kidney

Liver

Pancreas

Islet  
cells

At same time  
Pancreas- Kidney

At same time  
islet- Kidney



Have you had any other kind of transplant? If you have, please tell us about it in the box



7. How many years has it been since your transplant?

Less than 1 year

1 – 3 years

3 -5 years

Over 5 years



8. How long were you on the waiting list for your transplant?

Less than 1 year

1 -3 years

More than 3 years



## Section 2

### Communication, Education and Advice.

It is important to have good communication between patients, transplant teams, local specialists and GP's.

The questions here will help us to understand what your experience was like. It will also help us to make things better where they are needed.



9. How good was the communication with the healthcare teams before your transplant

At referral with your GP?



Not good



okay



Good



Very Good

None of these



At referral with the  
local referring team



**Not  
good**



**Okay**



**good**



**Very  
good**

**None of  
these**

When you were being assessed.

Was the communication with the  
transplant team:



**Not  
good**



**Okay  
Sure**



**Good**



**Very  
Good**

**None  
of  
these**



When you were on the waiting list was  
the communication with:

the transplant team:



Not  
good



Okay



Good



Very  
good

None  
of  
these

Yes

Not  
Sure

The local referring team



Not  
good



Okay



Good



Very  
Good

None  
of  
these



Your GP



Not good



okay



Good



Very good

None of these



10. After your transplant how good was the communicate with the healthcare teams:

In the 1<sup>st</sup> year with the transplant team



Not good



Okay



Good



Very Good

None of these

From the end of the 1<sup>st</sup> year until now with:

The transplant team



Not good



Okay



Good



Very Good

None of these

From the end of the 1<sup>st</sup> year until now

with the referral team



Not good



Okay



Good



Very Good

None of these

From the end of the 1<sup>st</sup> year until now with your GP



Not good



Okay



Good



Very Good

None of these



**11. Do you feel able to contact your transplant team for advice by:**

Telephone



Yes



No



Do not know

By email



Yes



No



Do not know

By using a portal or a website



Yes



No



Do not know



12. Before your transplant do you feel you were given enough information from the transplant team:

During the referral process



Not good



Okay



Good



Very good

None of these

When you were being  
assessed



Yes



Not  
Sure



Good



Very  
good

None  
of  
these

When you were on the waiting list



Not  
Sure



Yes



Not  
Sure



Yes

Not  
Sure

Was the information easy to  
understand?



Yes



No



None  
of  
these



13. After your transplant do you feel you got enough information from the transplant team?

In the 1<sup>st</sup> year



Not good



Okay



Good



Very good

None of these

from the end of the 1<sup>st</sup> year until now



Not good



Okay



Good



Very good

None of these





Was the information easy to understand



Yes



No



None  
of  
these

14. Do you know about the information you can get online about living with a transplant?



Yes



No

If you ticked yes, please tell us on next page what information was useful to you.



If you ticked yes, can you tell us how helpful the following information was to you

NHS Blood and Transplant website



Unhelpful



Helpful



Not  
helpful or  
unhelpful



None  
of  
these

Transplant Centre website



Unhelpful



Helpful



Not  
helpful or  
unhelpful



None  
of  
these

### Local hospital website



Unhelpful



Helpful

Not helpful  
or  
unhelpful



None of  
these

### Patient Support Group



Unhelpful



Helpful

Not helpful  
or  
unhelpful



None of  
these

### Charity Support Group



Unhelpful



Helpful

Not helpful  
or  
unhelpful



None of  
these



15. If you know about any other places online that give you information on living with a transplant,

Please tell us in the box below.

A large, empty, rounded rectangular box with a black outline, intended for writing an answer to question 15.



16. Can you think of ways to make it easier to get information.

Please tell us in the box below

A large, empty, rounded rectangular box with a black outline, intended for writing an answer to question 16.

### Section 3

#### Emotional and psychological support.



Psychological feelings are feelings that you have in your mind.

This section will help us to understand if we helped you with these things.



It will also help us to see what we could do better.

17. Before your transplant what was the support for your emotional needs like from the healthcare team:

During the referral process



Not good



okay



Good



Very Good

None of these

When you were being assessed



Not good



okay



Good



Very Good

None of these

When you were on the transplant waiting list



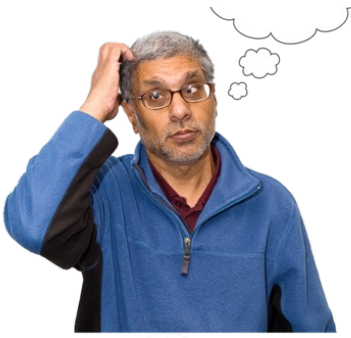
Not good



okay



Very Good



18. After your transplant do you think you got support from the transplant team for the things in your mind:

In the 1<sup>st</sup> year



Not good



okay



Good



Very Good

None of these

From the end of the 1<sup>st</sup> year until now



Not good



okay



Good



Very Good

None of these



20. Apart from your family where did you get the most support for the things on your mind?

Please tick all the ones you think you got help from.

Transplant co-ordinator/specialist nurse

Other member of the Transplant team

Peer (someone who has had a transplant)

Charity group

Counsellor

Clinical psychologist

GP

Psychiatrist

None of the above





If you got help for things on your mind from somewhere else, please tell us about it in the box below.

A large, empty, rounded rectangular box with a pointed bottom, intended for writing. The box is outlined in black and has a white interior. The top corners are rounded, and the bottom edge has a small triangular point extending downwards.





22. If you think there are other ways that would have helped you better, please tell us about them in the box below.



**This section helps us to understand what it is like for you to travel to the transplant centre.**

23. Please tell us what travelling to the transplant centre is like for you.

Travelling to the transplant centre is hard for you.



Yes



No



None of these



If you answered yes it was hard,  
please tell us why in the box below.

## **Section 5**

### **Support and care for you after the transplant.**

Since Covid-19 some transplant centres have changed how they do things.

They use video consultations called “Near Me”. They also use telephone consultations.

These mean patients do not need to travel to appointments.

What you tell us will help us to think about how the changes have affected you .

It will also help us to think about how to make things better.



Do you have digital access at home?

This could be with a phone, tablet laptop or computer.

## 24. Digital access in your home

**Do you have internet access at home?**



Yes



No



None of these

**If not, is there somewhere else that you can access the internet?**



**Do you have access to the internet via laptop/tablet/mobile phone?**



**Have you been able to access the IT systems used for remote consultations (such as Near Me)?**





If it is hard for you to use any of these ways, please tell us why in the box below.

25. Please tell us about what it was like for you to use any of these ways for your consultations

Have remote video consultations been helpful?



Yes



No



None of these

Have telephone consultations been helpful?



Yes



No



None of these

Do you feel you have enough face-to-face follow up at the transplant centre?



Yes



No



None of these

Would you prefer a mixture of remote and face-to-face appointments?



Yes



No



None of these



## 26. Choices

Are you given the choice of the kind of appointment to have?



Yes  
always



Yes  
sometimes



No



None of these



27. What are the good things for you about a face to face appointment .

Please tell us in the box below.



28. Is there anything that would work the best for you?

Please tell us in the box below.

## Section 6

### Monitoring you from a distance.



**Transplant patients need to be checked regularly. This includes blood tests. These tell us how a new organ is working. It also tells us your medication levels.**

29 Blood tests related to your transplant

Can you get blood tests taken locally?



Yes



No



Do not know



If you ticked yes , please tell us where you usually get your bloods taken.

GP

Community hub

Local specialist centre or local hospital





Is there any other place you would go to get your blood tests taken?

Please tell us in the box below.

### 30. Remote monitoring systems.

Do you use any remote monitoring systems?

For example these could be to check your blood pressure or heart rate



Yes



No



Not Sure



If you answered yes, please tell us more about what you use in the box below



31. Is there anything that would work best for you.

Please tell us in the box below.

A large, empty, rounded rectangular box with a pointed bottom, intended for writing an answer. The box is outlined in black and has a white interior.



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