Your Pancreas Transplant

Information for patients

Contents

1. Introduction

This booklet has been written to provide you with a range of information about pancreas transplantation. Together with information which you will receive from the Transplant Surgeon and the Transplant Recipient Coordinator during your presentation clinic appointment, it will give you a greater understanding of what having a pancreas transplant involves.

Pancreas transplantation is a treatment option for people with diabetes. A successful transplant can help you to achieve normal blood sugar levels and means you will no longer need to inject insulin. It also has beneficial effects on the other complications of diabetes, including damage to eyesight, nerves or the heart and blood vessels. In the UK we perform over 200 of these transplants a year.

Transplant types

There are different types of pancreas transplant that we carry out:

Simultaneous Pancreas Kidney transplant (SPK):
This procedure is performed if you have diabetes and progressive kidney failure, are on dialysis, or are close to needing dialysis. You will receive a pancreas and kidney transplant during the same operation.

Pancreas Transplant Alone (PTA):
This procedure is reserved for people who have type 1 diabetes and who suffer from frequent hypoglycaemia (very low blood sugars), which usually requires urgent medical attention or help from another person to treat it. It is an option for diabetics who have very labile (or unstable) sugar control that is difficult to manage, despite maximum treatment. Your referring Consultant may decide with you that a pancreas transplant may be the best treatment for you.

Pancreas after Kidney transplant (PAK):
This procedure is performed if you have diabetes and have already received a kidney transplant that is working well, but would benefit from a return to normal blood sugar control without insulin. You will receive a pancreas transplant only.

Islet after Kidney Transplant (IKA) is a transplant of islet cells (insulin producing cells) after a kidney transplant from different donors.

Combined Islet Kidney is a transplant of islets and a kidney from the same donor. It is a transplant for patients with diabetes type 1 who also have renal failure that may not be fit enough for a combined kidney pancreas transplant.

2. Where do donor organs come from?

Deaceased pancreas and kidney transplants

The term 'deceased donor (or cadaveric) transplant' is used to describe a transplant pancreas that has been removed from someone who has died. There are two types of cadaveric donor; Deceased after Brain Death (DBD) and Deceased after Circulatory Death (DCD). Consent is always sought from the donor's relatives before the pancreas is used, even if the donor's wishes were already known.

- **Deceased after Brain Death (DBD) donors**
  'DBD' donors are patients who have suffered permanent and irreversible brain injury, and are classed as 'brain stem dead'.

- **Deceased after Circulatory Death (DCD) Donors**
  'DCD' donors are patients whose organs are removed soon after cardiac arrest, when their heart has stopped beating. These patients have usually had a brain injury but are not brain stem dead and a

decision has been made to withdraw treatmentt so not to prolong life when they have no chance of recovery

The most recent survey of UK data by NHSBT (National Health Service Blood and Transplant) indicates that success rates for DCD donor transplants are very similar to those achieved for DBD donor transplants. However, delayed graft function (see page XX) is more common with DCD transplants.

Are there any risks from having a transplant?

All organs are assessed to find out if they have any infection or illness that could be passed to potential transplant recipients. Every possible precaution is taken to prevent the transmission of viral infections, cancer or any other potential life threatening condition to patients who receive an organ for transplantation. Whilst every effort is made to gather this information, we are unable to give a 100% guarantee that the organ that you will receive is completely free of risk factors.

If there are any special risk factors associated with a donor over and above those described, they would be discussed with you immediately before any transplant procedure.

Living kidney donation

In some circumstances it may be worth considering whether a kidney transplant on its own from a living donor is the best option for you, instead of the combined kidney and pancreas transplant. Your assessing team will discuss this possibility with you in clinic, if it is felt to be appropriate based on your individual situation or medical history.

Living donors are people who are otherwise well and would like to donate one of their healthy kidneys to you.They are often a close relative. They can also be people who are not related to you but with whom you have an established emotional relationship, such as a partner or close friend Whether a person is suitable for giving you one of their kidneys will depend on their overall health, whether they have any other significant medical problems and whether both of their kidneys function normally. Please ask for further information about eligibility for donation and what happens when someone wants to donate you their kidney.

If you have a living donor kidney transplant it is still possible to consider a pancreas transplant or an islet cell transplant after your kidney transplant.

3. What does the pancreas do?

The pancreas lies behind the stomach in the abdomen. It has two main functions. It produces juices that help with the digestion process and it also produces insulin from small clusters of cells called ‘islet’ cells within the pancreas. Insulin is responsible for lowering blood sugar levels. If you have diabetes, you no longer produce insulin and need insulin injections to keep your blood sugars within normal limits.

4. What is the benefit of having a pancreas transplant?

The main aim of a pancreas transplant or a combined kidney and pancreas transplant is to improve both the quality and the length of your life. Transplantation offers freedom from insulin injections and, in the case of a combined kidney and pancreas transplant, freedom from dialysis. Diabetes causes a number of life threatening complications which may well be reduced or halted as a result of having a pancreas transplant. In the case of Simultaneous Pancreas Kidney transplant (SPK), a functioning pancreas transplant can protect the new kidney from damage caused by uncontrolled blood sugars.

5. Relevant investigations

At your initial consultation, you will go through a thorough medical assessment with the Transplant Consultant and Transplant Recipient Coordinator (Specialist Nurse).

You will also be asked to arrange a dental review if you have not visited the dentist recently so that any infections or other problems can be treated before your transplant. This is important, because after your transplant you will take anti-rejection medications which can alter your body's ability to fight infections. If you are a woman, we will need you to be up to date with relevant general health screening. This includes mammography (breast screening) every 3 years for women over the age of 50 and cervical smear tests every 3 to 5 years between the ages of 25 and 64. These should be arranged through your GP.

Included in your review will be an assessment of any other medical conditions you may have. Depending on what these are, you may then be referred for some additional tests. As with all surgical procedures we will assess you to make sure that you are fit enough for the operation. In addition to blood tests, chest X-RAY and an ECG (heart tracing), you may need the following tests which will either be arranged locally or in the transplant unit:

ECHO cardiogram

We usually ask your referring doctor to do a scan of your heart called an ECHO cardiogram**.** This provides us with information about the function of your heart.

Exercise tolerance test

All potential kidney/pancreas transplant patients usually require an exercise tolerance test or a test called a **Cardio Pulmonary Exercise** test or **CPEX** for short. This test will look at your heart and lung function whilst you are exercising on an exercise bike. This looks at an operation.

Myocardial Perfusion Scan (MPS)

This test (also known as a thallium stress test) shows blood flow into the heart muscle at rest and during exercise. This is done to see how your heart performs performs under stress. If your MPS test is abnormal the assessment team may request a **coronary angiogram** which can determine whether your heart arteries are narrowed and where they are narrowed. During angiography, a thin flexible tube (catheter) is threaded through an artery of an arm or leg, up to the heart and a dye is then injected into the catheter. The Doctor will then have a picture to see if any of the heart blood supply is blocked and how well the heart is beating .

CT or MRI scan

You may need to have an imaging studies of the blood vessels in your pelvis and legs. This can either be done by a CT or an MRI scan. A series of pictures are taken by an image intensifier to look at the arteries and veins mainly in your legs and abdomen. This will show if any of them are blocked and whether the arteries and veins are good enough to transplant a kidney and a pancreas without compromising the blood supply to your legs and other organs. Another way to assess your arteries and veins in the pelvis and groin area is with an ultrasound scan called a **Doppler Scan.**

6. How long will I wait for a transplant?

How do I get onto on the waiting list?

If all of your test results are within normal limits then the Consultant Surgeon will put your name forward to be placed on the transplant waiting list. Whether you are suitable for a pancreas transplant will be discussed at a weekly meeting of surgeons, heart specialists, anaesthetists and specialist nurses. If it is agreed that you are suitable, you will be added onto the transplant list.

The Transplant Recipient Coordinator will contact you after this meeting and advise you of the outcome.

Occasionally some people are felt to be too high risk or not suitable to receive a transplant and are declined the option of a pancreas transplant. In this situation, your care would be referred back to your original Consultant. The reason for this decision would be fully explained to you. There may be other transplant options for you which include kidney transplant alone, islets transplant, or possibly a combined kidney and islet transplant.

How long will I be on the waiting list?

Once you and the Transplant team decide that a pancreas transplant is an acceptable option for you, the next step will be waiting for the organs to become available. Your name will be added to the National Transplant waiting list for either a combined kidney pancreas transplant or pancreas transplant alone.

It is not possible to predict how long you will have to wait, but as a guide, the average waiting time is between 12 and 24 months. It may be shorter or longer than this, depending on your individual circumstances.

When the Consultant Surgeon On-call at the Transplant Centre is told of a potential pancreas (and kidney, if needed) becoming available, then the person who is the best match for that transplant will be called in. This person is selected based on a number of factors, including how long they have been on the waiting list. This process of matching the recipient to a suitable donor is carried out through a national allocation scheme.

What happens while I am on the waiting list?

Your local diabetes or renal specialist will continue to monitor your condition and kidney function. If there is any significant change in your medical condition this will be reported to the Transplant Unit. Regular blood samples will be sent to the Transplant Immunology (Tissue Typing) laboratory. This sample will be needed when potentially suitable donor organs become available, as it is essential for final matching with the organ/s. It is extremely important that you have this blood sample taken and sent reliably because, if an up to date sample is not available in the laboratory, this may prevent you from receiving a transplant on that occasion.

We will offer you an appointment to be seen by us each year to confirm that you still want to receive a transplant and to assess your physical fitness. We may also organise an annual heart stress test or other investigations to check on how well your heart is working and your fitness for surgery. It is important to keep in touch with us and tell us about any changes to your health or medications, throughout your time on the waiting list.

While you are waiting for your transplant your local team will monitor your health as usual. They may request additional tests and procedures for you. If you are concerned about this, please contact us (see phone numbers at the end of the leaflet). We would also encourage you to look after your general health in the best way you can and keep an eye on your weight. If you are a smoker, you should seek help to stop as the combination of smoking and diabetes increases your risk of heart disease and blood vessel disease which not only affects your health but may also affect your chances of having a successful pancreas transplant.

7. Important points to remember while on the waiting list

Change of circumstances: When you are listed on the transplant waiting list, you must tell the Transplant Recipient Coordinator immediately of any change in your circumstances, such as change of address, telephone number, or if you are admitted to any hospital.

Dialysis

If you are not on dialysis when you are first assessed in the clinic, but you then start haemodialysis or peritoneal dialysis, please telephone Transplant Recipient Coordinator to let them know. This is important as you are more likely to be considered for a transplant if you are already established on dialysis.

Blood transfusions

Once you are active on the transplant list you must tell us immediately about any blood transfusions that you receive because this may affect your antibodies to potential donor organs. We will ask you to send us additional monthly blood samples to check for antibodies that you may have acquired from the blood transfusion.

24 hour availability

Please make sure that your mobile phone is always switched on and that you have given us all the phone numbers where you might be at any time. Please do not have your answer machines on, especially at night, as we may be trying to call you for a transplant and we will not leave a message. The Transplant Recipient Coordinator has a limited amount of time in which to call you in for the transplant when a donor organ becomes available. If we cannot get hold of you we will call the next suitable person on the list.

If you go on holiday

Tell your transplant co-ordinator if you are going on holiday, as they will need to suspend you from the list while you are away.

If you change your mind

If you decide a transplant is not for you, please let your Transplant Recipient Coordinator know immediately so we can take you off the waiting list.

Transport arrangements for your transplant

In the event of you being called in for a transplant, it is important that you have a plan in place to get to the Transplant Unit as soon as possible. This could be at any time of the day or night so keep a bag pascked.

You will usually need to make your own transport arrangements to get to and from the Transplant Unit. If you think you might have problems arranging transport, please discuss this with us.

8. What happens when I am called in?

When the Transplant Recipient Coordinator calls you (which often will be in the middle of the night), they will ask you about your general health and, if you are on dialysis, what mode of dialysis you are on and when you last had dialysis.

The Transplant Recipient Coordinator will give you advice about eating and drinking, in preparation for the surgery. You will be asked to come to the Transplant Ward (see attached information for details). It is important that you arrive as soon as possible and by your own means of transport if possible.

The Transplant Recipient Coordinator has a very limited time in which to contact you as the donated organ must be used within a certain time period. If you cannot be contacted quickly they will have to identify an alternative patient to offer the transplant to. This is why it is so vital that you remain contactable at all times.

There may be times when we call you in for your transplant and we are unable to go ahead with your operation. This can be because we have received new information about your donor, or the organ may be damaged and therefore not suitable for transplant. In order to give you the greatest opportunity to receive a transplant we will ask you to start your journey once we have accepted the offer of an organ. If the Transplant Recipient Coordinator then receives new information about your donor which means your transplant cannot proceed, they will call you and ask you to return home. We do understand that this can be emotionally difficult and we will do our best to ensure you are kept informed at all times.

What happens on the ward?

When you arrive on the ward the nurse will show you to your bed. They will ask you some questions about your general health and dialysis. Occasionally there may not be a bed immediately available, however staff will do their best to make you feel comfortable within the ward environment and will find a bed as soon as possible.

The doctor and anaesthetist will come and examine you and ask more questions to make sure you are in good health for the operation. You will have further blood samples taken and the ward staff will carry out an ECG (a tracing of the electrical activity of your heart) to make sure that you have not developed any new heart problems.

You will also be asked to sign a consent form for the operation. If there is anything you do not understand or would like further information about, please ask before signing the consent form.

You may need to have dialysis before you can have the operation. The ward nurses will arrange this for you.

9. What does the operation involve?

A pancreas and kidney (if required) from the same donor will be transplanted at the same time. A pancreas transplant alone operation takes 3-4 hours. A combined kidney and pancreas operation about 4-6 hours.

The operation is performed under a general anaesthetic and is usually performed through one cut (incision) in your abdomen, from below your breastbone to below your bellybutton.

The surgeon will place the pancreas in one side (usually the right side) of your abdomen and the kidney (if required) on the opposite side (usually the left). Your own pancreas and kidneys will remain in place. The operation involves connecting the blood supply of the organs to the vessels that take blood to your legs. In addition to connecting these blood vessels, another connection has to be made into your small intestine or to your bladder to drain the digestive juices that the pancreas produces.

You appendix is uaually removed as part of the operation If you have a diabetic complication called gastroparesis (where you have difficulty absorbing food and medications), the Consultant Surgeon may insert a special tube called a jejunostomy directly into your small intestine at the same time as the transplant. Alternatively a a small feeding tube will be introduced through your nose. This will allow us to give you food, fluids and medications into your intestine immediately after your transplant. This tube will be removed as soon as possible. We will discuss this with you while you are on the ward.

In a combined kidney pancreas transplant the pancreas is usually connected to your bowel. However if you receive a pancreas transplant alone, the surgeon may connect your new pancreas to your bladder at the time of your operation. This is called “bladder drainage” and your new pancreas will produce juices that will drain into your bladder and be passed out of your body in your urine. This enables us to easily analyse your urine to check the level of an enzyme called amylase, in order to see how well the graft is functioning.

If the side-effects are affecting the quality of your life, the transplant surgeon may advise we change the connection from your bladder to your bowel. This would require a further smaller operation and the procedure and timing of this will be explained to you by the Transplant team.

The following picture shows you where the pancreas and kidney are placed in the abdomen during a transplant.

10. Where will I be cared for after my transplant?

After the transplant you will be cared for in the Intensive Care Unit (ICU) or High Dependency Unit (HDU). This is because of the length of time you are under the anaesthetic and the need to monitor you closely after your surgery. When you are well enough you will be transferred to the Transplant Ward.

Waking up in the Intensive Care Unit (ICU) or the High Dependency Unit (HDU)

After your surgery you will wake up in the ICU or HDU. These are some of things you can expect.

You may experience some pain and discomfort, but you will have a special infusion pump attached directly to a vein in the back of your hand or arm to give you pain relieving drugs. This is called a **PCA** and stands for 'patient controlled analgesia'. You can press a hand-held button when you feel pain or discomfort and the pump will deliver a pre-programmed dose of pain killing drugs directly into your vein.

You will have an **intravenous line** (a sterile plastic tube inserted into a vein) in both your arm and your neck. This will be used to give you fluids and drugs for the first few days after your surgery. You will also have a **urinary catheter** in place so we can measure the volume of urine you are passing. You will need to have this in place for at least 5 days.

You will have a **nasogastric tube**, which is a thin tube that is passed into your nose and down into your stomach. It helps to keep your stomach empty or 'decompressed', to protect the area where your new pancreas is attached to your small intestine. You may also have one or more **abdominal drains** in place, to help remove any excess fluid from your abdomen.

You will need physiotherapy to help you to clear your chest and cough effectively following your surgery. This helps to prevent you from developing chest infections. You will also have an oxygen mask on your face after your surgery, to ease your breathing. You will need to wear this for 24 to 48 hours, or until the medical team caring for you tell you that you no longer need it.

If you have also had a kidney transplant, you may need to have temporary dialysis, just until your new kidney starts to function.

On the Transplant Ward

When we feel you have recovered enough, you will be transferred back to the Transplant Ward. You will be monitored very closely by the nurses and doctors. Nursing staff will regularly measure how much urine you are passing and your blood sugar levels. They will also check your blood pressure, pulse and temperature several times a day. You will have daily blood samples taken for analysis in the laboratory, to accurately check on the function of your new organ/s, as well as the drug levels of your anti-rejection medication.

You will be attached to a monitor that will measure your blood pressure, pulse and oxygen level. You will continue to have an intravenous line in your neck and/or arm for fluids and drugs, as well as the patient controlled analgesia (PCA) for pain control. This will be removed when you can take your painkillers by mouth. You will also continue to have your catheter, nasogastric tube and abdominal drains in place. These tubes and lines will gradually be removed as your recovery progresses.

Your blood sugar levels will be checked at regular intervals, so that we can monitor how well your new pancreas is working. You may receive some insulin in the early days after your operation. The

Whilst you are an inpatient on the Transplant Ward we may carry out a special ultrasound called a Duplex or CT scan. This scan looks specifically at the blood flow of your new pancreas (and kidney, if required). The scan will show up any narrowing or blockages of the blood vessels.

11. How long will I stay in hospital?

How long you need to stay in hospital will depend on your progress following the transplant. The usual length of stay is 2-3 weeks. During this time the function of your new transplant will be monitored very closely.

Day by day you will feel stronger, become more able to move around, and be encouraged to start taking care of yourself little by little. As you feel better, you will be given time to learn about your new medications and how to take care of yourself and your new transplant when you are discharged home.

12. Delayed graft function

Sometimes the transplanted kidney does not work immediately. This is called **delayed graft function**. During this period we will closely monitor you. If you were previously on haemodialysis, you will need to continue with this until the new kidney starts to work properly; this may take a few days. If you were on peritoneal dialysis you may need temporary haemodialysis, as you will not be able to have peritoneal dialysis after your transplant surgery. During this time tests will be done to try and find out the cause of the delayed function.

13. What drugs do I need to take?

In order to protect your transplanted pancreas (and kidney, if also transplanted) from rejection by your immune system, you will need to take powerful medications called immunosuppressant drugs. Although these drugs protect your new transplant from rejection, they also reduce your ability to fight some infections . This means that you will also need to take other medicines that will protect you from the infections to which you are vulnerable.

The dosage of the immunosuppressant medications will be reduced over the next few months, following your transplant, however you will still need to take these medications for life, or as long as your transplant is functioning. **You should never stop taking these medications**. If you were to stop taking the immunosuppressive medications your new pancreas (and kidney, if transplanted) would stop working and would be rejected by your body.

At the time of your operation you will receive treatment either with Alemtuzumab (Campath) or Basiliximab. These drugs reduce the ability of your immune system to reject your transplanted organs. This is then followed by long-term drug therapy, most commonly with a combination of two drugs, tacrolimus and mycophenolate. As with all medications, these drugs have some side-effects. However, it is important to remember that you may not experience all or any of these. Please speak to a member of the Transplant team if you are having problems with side-effects, as there may be an easy solution. Common side-effects of these medications are listed below.

Tacrolimus

- shaky hands
- upset stomach (usually when first taking this medicine)
- sleep disturbances
- increase in blood pressure
- an increase in blood sugar (diabetes); this will be monitored by us

using blood or urine tests

- hair loss
- mood changes
- headaches.

Mycophenolate

- the most common side-effect is a drop in white blood cell count. This puts you at risk of infection. We will monitor your blood count and adjust your medication if needed.
- upset stomach including diarrhoea, nausea and vomiting
- a rash.
-

Research is on-going into new anti-rejection medicine, with the aim of reducing the side-effects and prolonging the life of the transplant. We will let you know if there are any new medicines that become available.

Self-medication training

Once you are comfortable after the operation you will begin to learn about your new medications. These will be listed on a medication record card and the pharmacist will see you to go through and explain what they do and how to take them. You will then start to take your medications yourself, closely supervised by the nursing staff.

Once you are confident with taking your new medications, and the nursing staff are happy that you are taking them correctly, you will be able to take your medications unsupervised, as you would do at home. This training aims to help you become familiar and confident with taking all your new medications before you go home.

Long-term immunosuppression medication

Long-term immunosuppression medication puts you at a higher risk of developing some forms of cancer, such as lymphoma (cancer of the lymph nodes/glands) and skin cancer. We will monitor you closely for any signs of these cancers after your transplant, as they can usually be effectively treated if found early. We will also give you advice about skin care protection, including sun protection.

Infections

As the anti-rejection medications suppress your immune system, you will be at greater risk of infections. These infections can be more serious as your body is not able to provide its usual response to infection while your immune system is lowered. You are most vulnerable for the first three to six months after your transplant.

The majority of these infections, such as wound, urinary and chest infections are caused by relatively common bacteria, which are usually easily treated with common antibiotics. However, because of your immunosuppressant drugs you are also susceptible to more serious diseases from rarer infections such as Cytomegalovirus (CMV), fungal infections and pneumocystis jurovecii (PJP). Chicken pox may cause a serious illness while you are taking the immunosuppression tablets. Before we add you to the transplant list, we will check your immunity to chicken pox. If you are not immune, we will ask your GP to vaccinate you against this virus. Even if you do have immunity, you will still need to avoid close contact with anyone who has chicken pox or shingles.

14. What are the risks of transplant surgery?

With all transplant operations there are associated risks and potential for problems to occur during the operation and afterwards. The most common problems are listed below.

- **Delayed function**
  Delayed graft function in less than 10% (10 out od 100) of pancreas transplants. This is less common than in kidney transplant (which can occur in up to 40 in one hundred donor transplants) . While waiting for a pancreas to function you will need some insulin and while waiting for the kidney to start working you will probably need dialysis.

- **Bleeding**
  As with all operations, there is a risk of excessive bleeding. This is more likely in pancreas transplantation, as a number of medications and infusions are given after the operation to keep the blood thin and prevent thrombosis (clotting) in the pancreas graft. Approximately 10% of patients (10 in 100) have some bleeding after transplantation that requires a return to the operating room, to check on the pancreas and control any bleeding.

- **Thrombosis**
  There is a risk of a blood clot forming in the blood vessels to the transplant. This is called a thrombosis and can occur in 2 out of every 10 patients (20%). It can lead to the failure of the pancreas (or kidney). This is most likely to happen during the first week after the transplant and may result in the organ being removed. You will be monitored very closely for signs of this while you are in hospital and when you return home. You will have regular blood samples taken to measure how effectively your blood is clotting. You will be given various drugs to minimise the risk of a blood clot forming. However, these drugs can increase the risk of bleeding.

Pancreatitis is inflammation of the pancreas and can make you very sick. This occurs because of damage to the pancreas during the process of re-warming it with your blood, after it has been stored on ice before the transplantation. If you develop graft pancreatitis you may need to have further surgery to wash out any fluid collections, or you may have tubes placed into your abdomen, to drain these fluid collections. Pancreatitis of the transplanted pancreas usually gets better on its own, but approximately 5-10% of people (5 to 10 in 100) who develop this problem will need the transplanted pancreas to be removed.

- **Duodenal Leak**

  The pancreas is joined to either your bowel or your bladder. There is a small chance that this can leak which will require a re-operation (approximately 5%, 5 out of 100 patients)

- **Urine leak**

  For those who have had a kidney transplant there can occasionally be a leak where the ureter (urine drainage tube) joins your bladder. This usually requires a return to theatre and an operation to have the leak repaired.

- **Further operations**

  Overall approximately 1 out of every 5 people who have a pancreas transplant will need to go back to theatre for a further operation to deal with any of the above complications, should they arise. This may be followed by a further stay in Intensive Care or the High Dependency Unit.

- **Other complications**

  The general risks are similar to those following any type of major abdominal surgery, including wound infection, infection inside the abdomen, cardiac (heart) complications, deep vein thrombosis (blood clots in the legs) and pulmonary embolism (blood clots which move to the lungs)

- **Complications of immunosuppression**

  In the early days following a transplant, the surgery and the immunosuppressant drugs make your body more vulnerable to chest, urinary and other types of infections. You will be given antibiotics and anti-viral drugs to help prevent and treat any active infection.

- **Rejection**

  Your body's natural immune response is to try and get rid of the new organ, by using white blood cells to attack it. Immunosuppressant medications help to control this response. However, rejection will still occur in about 1 in 4 transplants. Rejection can affect the pancreas or kidney, or both organs at the same time. In order to find out whether your body is rejecting the organ you may need a biopsy. This is a sample of the organ that is collected using a long needle. This is carried out using local anaesthetic to numb the area where the needle is to be inserted. Rejection can usually be treated successfully with additional immunosuppressant medications.

15. Patient and Graft Survival

As with any major abdominal surgery and anaesthetic, there are risks to life. Your Consultant Transplant Surgeon will discuss the balance of risks and benefits with you at your assessment. This will include any specific risks that may apply to you.

The National Blood and Transplant Service statistics show that 1 year after a pancreas transplant 97% of patients (97 out of 100) are still alive and at 5 years 88% of patients are still alive (88 out of 100).

The National Blood and Transplant Service statistics show that in Simultaneous Pancreas Kidney (SPK) transplants the transplanted pancreas remains working after 1 year in 87% of people (87 out of 100). After 5 years this figure falls to 75% (75 out of 100 people).

In pancreas alone transplant (where there is no kidney transplanted), the National Blood and Transplant Service statistics show the transplanted pancreas remains working after 1 year in 75% of people (75 out of 100). After 5 years this figure falls to 45% (45 out of 100 people).

16. What happens to the transplanted kidney if the pancreas has to be removed?

If the Pancreas is removed or fails you will need to re-start your insulin. In the majority of cases the kidney will not be affected and will continue to function. If you and your Consultant decide that you want to be considered for a further transplant you will be referred back to the Transplant team. We will then discuss with you the risks and benefits of a further pancreas transplant or Islet cell transplant

17. What happens when I am discharged from the hospital?

Once you have been discharged from the hospital you will still be monitored very closely. This is because changes in your condition can develop very quickly in the first few months after your transplant. For this reason you will need to visit the outpatient department up to three times a week after your transplant, to begin with. The frequency of your visits will gradually be reduced and adjusted, depending on your condition.

Your post-operative care will be shared between the transplant unit and your local centre. You will be told where your local centre is. How often you need to come to an outpatient appointment at the transplant centre will depend on which part of the country you come from. The doctors in the transplant unit will work very closely with your local centre.

If you have had a combined kidney and pancreas transplant then you will have had a stent placed in the ureter (between the kidney and the bladder). This will need to be removed 4-6 weeks after your transplant. This will either be in the transplant unit or at your local centre.

If possible, we recommend that you buy a blood pressure monitor, thermometer and weighing scales before you are called in for transplant, as you will need these after you are discharged, so that you can monitor your own health at home. Unfortunately they are not supplied on the NHS. Please ask a friend/relative to bring these into hospital before you go home, so they can be calibrated (set correctly).

The Transplant Centre will give you telephone numbers before you are discharged of who to contact should you feel unwell.

18. Consent for simultaneous pancreas and kidney transplantation

At time of inclusion on National Transplant List:	**Tick**
I have read and understood this patient information booklet explaining pancreas transplantation	☐
The following operative risks have been discussed and I understand:	
- Graft survival rates Pancreas (85 in 100 people at 1 year), Kidney (94 in 100 people at 1 year)	☐
- Non functioning kidney or pancreas transplant *(The kidney or pancreas never works)*	☐
- Delayed Graft Function (up to 40 in one 100 deceased donor transplants) *(There is a delay in the start of the kidney working)*	☐
- Infection/leak with re-operation (up to 15 in 100 people)	☐
- Bleeding requiring re-operation (up to 15 in 100 people)	☐
- Pancreatitis	☐
- Urine leak (2 in 100 people)	☐
- Thrombosis *(blood clot in the vessels, causing the kidney or the pancreas not to work)*	☐

- Episode of rejection after transplant (in up to 20 out of 100 people) ☐

- Cardiac complications ☐

- Blood clots in the legs (DVT) or lungs (PE) (1 in 100 people) ☐

- Death (approximately 3 in 100 people) ☐

The following aspects and risks of pancreas and kidney transplantation have been discussed and I understand:

- Appendectomy at the time of transplant ☐

- Donor specific risks were discussed, including transmissible infection (such as cytomegalovirus), or cancer(known/unknown) ☐

- Immunosuppressive treatment was discussed, including its associated risks (such as drug side effects, inf ection, diabetes and cancer, including skin cancer) ☐

- The process of long-term follow-up post-transplantation and the consequences of not following medical advice on graft survival was discussed ☐

- I have an understanding of current graft survival and mortality rates, as contained in this patient information booklet ☐

I confirm that I have understood and consent to the procedure. I will have the opportunity to ask questions and re-affirm my consent at time of review and prior to the operation itself.

Patient:

Signature……………………

Clinician:

Signature……………………

Date: /
/