

Commissioning Transplantation to 2020

Subgroup of the National Specialist Services Committee
Final Report

National Services Division



Table of contents

Executive summary.....	5
1. Background.....	7
1.1. Business case.....	7
1.2. Subgroup aims and objectives	8
1.3. Methodology	8
1.3.1. Activity forecasting	8
1.3.2. Capacity and financial modelling.....	9
1.3.3. Patient requirements.....	9
1.3.4. Public health and wider societal impacts of transplantation.....	10
1.3.5. Health and social care resource impact analysis.....	10
2. Public health and wider societal impacts of transplantation.....	11
2.1. Demand for transplantation.....	11
2.2. Demographics of transplant recipients	12
2.3. Impact of transplantation.....	12
2.3.1. Survival.....	12
2.3.2. Quality of life: Physical, psychological, and social health	13
2.3.3. Quality of life: Specific domains	15
2.3.4. Quality of life: Living donors.....	16
3. Quality	17
3.1. Existing quality indicators.....	17
3.2. Transplant psychiatry.....	19
3.3. Patient feedback	20
3.4. Management of medicines post-transplant.....	32
4. Activity	34
4.1. Historical activity	34
4.1.1. Waiting lists	34
4.1.2. Solid organ transplantation activity.....	35

Commissioning Transplantation to 2020	
4.1.3. Cardiothoracic transplantation activity	35
4.1.4. Abdominal transplantation activity	36
4.2. Future activity	37
4.2.1. Organ donation	37
4.2.2. Organ transplantation	39
4.3. Transplanted organs in patients in Scotland.....	42
5. Developments.....	44
5.1. Histocompatibility and Immunogenetics	44
5.1.1. Change in technologies	45
5.2. Therapeutic apheresis for renal transplantation	45
5.3. Novel Technologies in Organ Transplantation.....	46
5.4. Research opportunities	47
5.5. Potential designation of new national services	48
6. Finance	49
6.1. Context	49
6.2. Expenditure by service.....	49
6.3. Cost per case.....	50
7. Health and social care resource impact analysis.....	52
7.1. Background.....	52
7.1.1. Other relevant studies.....	52
7.1.2. Methodology	53
7.2. Impact.....	53
7.2.1. Costs	53
7.2.2. Benefits.....	56
7.3. Quality Adjusted Life Year (QALY).....	57
7.4. Valuation of QALYs.....	59
7.5. Estimated costs and benefits	60
7.6. Wider Economic Benefits	63
8. Conclusions	64

Commissioning Transplantation to 2020	
8.1. Activity and capacity	64
8.1.1. Adult heart transplantation	64
8.1.2. Adult Congenital Heart Disease (ACHD) transplantation	64
8.1.3. Paediatric heart transplantation	64
8.1.4. Lung transplantation	65
8.1.5. Adult renal transplantation	65
8.1.6. Paediatric renal transplantation	66
8.1.7. Adult liver transplantation	66
8.1.8. Simultaneous Pancreas-Kidney transplantation	67
8.1.9. Islet transplantation	67
8.1.10. Service sustainability	67
8.1.11. Supporting services	68
8.1.12. Developments	69
8.2. Service specifications	70
8.2.1. Service definitions	70
8.2.2. Quality indicators	70
8.2.3. Approaches to machine organ perfusion	72
8.2.4. Approaches to the care of patients	73
8.2.5. Follow-up and shared care arrangements post-transplant (i.e. aftercare)	74
8.3. Public health and wider societal impacts of transplantation	76
8.4. Health and social care resource impact analysis	77
9. Summary of recommendations	78

Executive summary

This report sets out the recommendations of the Commissioning Transplantation to 2020 Reference Group on the future of solid organ transplantation services for Scottish residents.

Two complementary strategies were published in summer 2013 by the Scottish Government¹ and NHS Blood and Transplant,² which aspire to increase overall deceased donation rates from 17.9 per million population (pmp) in 2012/13 to 26.0 pmp in 2019/20 and deceased donor transplantation levels from 65.8 to 74.0 pmp.

All solid organ transplant services are nationally commissioned by National Services Division (NSD). An initial impact assessment undertaken by NSD has suggested that implementation of the strategies is likely to increase solid-organ transplantation levels in Scotland by 48% from 344 in 2012/13 to around 510 transplants in 2019/20, with increases in the number of transplants using organs from both deceased and living donors. In order to meet this significant growth in levels of transplantation activity, the capacity and demand of the Scottish solid-organ transplantation services need to be considered.

The National Specialist Services Committee (NSSC) recommended that an expert subgroup of the NSSC be established to consider the potential impact of a significant increase in the availability of donor organs. This NSSC subgroup was established to act in an advisory capacity to the NSSC and to support National Services Division in the forward-planning of the solid-organ transplant services. Group membership included relevant clinical, managerial, and financial representatives from NHS Blood and Transplant, NHS Greater Glasgow and Clyde, NHS Lothian, NHS National Services Scotland, NHS National Waiting Times Centre Board, NSSC, and the Scottish Government, as well as transplant recipients.

In reviewing the available evidence and forming recommendations, the group undertook a comprehensive review of the potential future of organ transplantation in Scotland, which included activity forecasts; required capacity, both within the transplant services and other interconnected services; potential developments which may impact on demand and capacity; and the appropriateness of the current service specifications. The group also considered feedback from transplant recipients, a health and social care economics analysis report, and a public health societal impact report to inform their final decision. This evidence is included throughout this report and the associated appendices.

The group has made a number of recommendations, which can be found in full below, but a summary of the general themes is provided here:

- Efforts should be made to improve the individual experience of the transplant patient pathway. This may include: streamlining the living donor process; developing more detailed patient information (e.g. through NHS Inform, PatientView, signposting to voluntary organisations); ensuring appropriate psychological support is available; creating individualised aftercare plans; and providing local outreach clinics.
- Work should be undertaken to further develop the transplantation services in Scotland, which could include: ensuring service sustainability through training and workforce development; continuing to pursue research opportunities; investigating

¹ Scottish Government (2013). A Donation and Transplantation Plan for Scotland 2013-2020. Available from: <http://www.scotland.gov.uk/Publications/2013/07/7461/> [Accessed 21 January 2015].

² NHS Blood and Transplant (2013). Taking Organ Transplantation to 2020. Available from: <http://www.nhsbt.nhs.uk/to2020/> [Accessed 21 January 2015].

the possibility of more nationally designated transplant services; and developing quality indicators to be measured and reported.

- Aftercare requirements should continue to be evaluated, particularly regarding the risks of inadvertent switching of medicines from branded to generic products and that of transplant recipients not receiving all required annual tests. Better communication links among the specialist units, local units, GPs, and pharmacists could help address these issues.

These recommendations have been made by the Reference Group and approved by the Commissioning Board. The group has requested that these be considered in light of the provided evidence and implemented as possible.

1. Background

1.1. Business case

Two complementary strategies were published in summer 2013 by the Scottish Government³ and NHS Blood and Transplant,⁴ which aspire to increase overall deceased donation rates from 17.9 per million population (pmp) in 2012/13 to 26.0 pmp in 2019/20, and deceased donor transplantation levels from 65.8 to 74.0 pmp. There is also expected to be an increase in the number of paediatric and adult living donor kidney transplants over the coming years.⁵

Within the Scottish Government's strategy, there is an aspiration for 'Scotland to be amongst the best performing countries in the world for donation and transplantation'. The NHS Blood and Transplant UK strategy for Living Donor Kidney Transplant also sets out the requirement to increase living donor kidney transplantation levels.

All solid organ transplant services are nationally commissioned by National Services Division (NSD).⁶ An initial impact assessment undertaken by NSD has suggested that implementation of the strategies is likely to increase solid-organ transplantation levels in Scotland (including adult renal) by 48% from 344 in 2012/13 to around 510 transplants in 2019/20, with increases in the number of transplants using organs from both deceased and living donors.

In order to meet this significant growth in levels of transplantation activity, the capacity and demand of the Scottish solid-organ transplantation services need to be considered. Increased transplantation levels may also bring the benefit of reducing pressures and costs in other associated areas of treatment including dialysis, insulin therapy, hospital admissions (including critical care), medical management (which include some high cost drugs), and surgery.

The Scottish Government has also requested that NSD implement action 15 of their strategy, namely to 'continue to monitor aftercare requirements across Scotland, as well as relevant developments in evidence and research, to ensure transplant recipients receive the support that they need. Consideration should be given to working with primary care and other parts of the NHS to raise awareness on longer-term post-transplant management'.

The National Specialist Services Committee (NSSC) recommended that an expert subgroup of the NSSC be established to consider the potential impact of a significant increase in the availability of donor organs in line with the aforementioned Scottish Government plan and the UK strategy. This NSSC subgroup would act in an advisory capacity to the NSSC and support NSD in the forward-planning of the solid-organ transplant services.

³ Scottish Government (2013). A Donation and Transplantation Plan for Scotland 2013-2020.

⁴ NHS Blood and Transplant (2013). Taking Organ Transplantation to 2020.

⁵ NHS Blood and Transplant (2013). Forecast renal transplant activity levels 2013-2020. [Paper provided to NSSC adult renal transplant short-life working group.]

⁶ Adult renal transplantation has recently gone through the process of consideration for national designation by the National Specialist Services Committee and is subject to become a two-site nationally-commissioned service as of 1 April 2015.

1.2. Subgroup aims and objectives

The proposed aims of the subgroup were:

- A. To forecast the future activity and realistic availability/capacity required leading up to 2020 for each of the services in scope:
 - Transplantation capacity required to meet need for each service per year
 - Associated outpatient capacity required
 - Live donor procedure capacity
 - Required workforce
 - Input from other associated services, e.g. Histocompatibility and Immunogenetics, Pathology, Independent Assessors, Skin Surveillance
 - Physical hospital capacity required, including (but not exclusively) wards, critical care, theatres, radiology
 - Developments which may impact on the demand, availability/capacity of the transplant services
- B. To ensure that the transplant service specifications are appropriate for the projected needs, including:
 - Service definitions
 - Quality indicators
 - Approaches to machine organ reperfusion
 - Approaches to the care of patients, including critical care, ECMO and VADs
 - Follow-up and shared care arrangements post-transplant (i.e. aftercare)
- C. To undertake a health and social care economics analysis costing report, looking at the resource impact (benefits/costs/saving) of implementing the subgroup's recommendations
- D. To undertake an assessment of the public health and wider societal impact of transplantation

1.3. Methodology

1.3.1. Activity forecasting

As part of 'Taking Organ Transplantation to 2020', NHS Blood and Transplant provided annual activity projections to the specialised commissioners across the UK.

The 'Commissioning Transplantation to 2020' NSSC subgroup derived the incidences by considering the NHS Blood and Transplant activity projections in light of UK Office of National Statistics 2012 population estimates, then applied this incidence to the Scottish population using General Register of Scotland 2010 and 2012 population estimates.

The group then considered these initial Scottish activity projections, in light of DBD, DCD and Living Donor organ availability trends and forecasts, rates of relevant underlying diseases in Scotland, historical transplant activity, and expert clinical opinion in order to make service projections.

1.3.2. Capacity and financial modelling

Acknowledging that the further that projections are made into the future, the less accurate they become, it was agreed that the services would model the required associated capacity relating to the forecast demand over the next three financial years (2015/16, 2016/17, 2017/18). In designing services around the needs of the patients, it was agreed that this modelling would take into consideration the feedback from the patient questionnaire, patient focus groups, and social research findings. In line with the financial constraints of the public sector, increased transplantation activity will have to be supported by increased efficiencies across the national services, including the transplantation services.

In modelling capacity, each service was asked to be realistic in their approach, to acknowledge the financial realities of the public sector, and to model from the bottom-up. Services were also asked to consider the impact of increased activity on other services within the provider hospitals. Meetings were held between NSD and each local operational management and finance team to sense check the approach to capacity planning, financial modelling, and the stated requirements.

The group acknowledged that no cognisance has been taken of the fact that increased investment in preventative measures, leading to a reduction in end-stage organ disease, would perhaps reduce the number of transplants required.

1.3.3. Patient requirements

Online questionnaire

An online questionnaire for solid organ transplant recipients was designed to capture information on the quality of the current service, identify areas for improvement, and help the Reference Group to understand better how a transplant has impacted on the lifestyles of transplant recipients. This questionnaire was developed in partnership with the Reference Group patient representatives. Patient engagement professionals, including the National Services Scotland Head of Public Participation and Engagement and the Scottish Health Council, were also consulted.

The questionnaire was hosted on NSS Surveys (LimeSurvey) and the link was promoted through press releases, transplant outpatient clinics, the Organ Donation Scotland Facebook page, NHS websites and social media, and numerous voluntary sector organisations. Participation was voluntary, and participants were informed that their responses would be anonymised and used for service improvement. Participants were also asked whether they would like to participate in a focus group, where in-depth discussion about their experience of the transplant pathway would take place.

Patient focus groups

The Scottish Health Council facilitated patient focus groups in locations close to where the majority of recipients who expressed an interest in attending the focus groups lived, and held a number of one-to-one interviews with others who were unable to attend but had expressed an interest in discussing their experience further. Focus groups and interviews were held in Edinburgh, Glasgow, Kilmarnock, Kirkcaldy, and Stirling to discuss a number of the key themes outlined in the feedback from the online questionnaire. These themes included:

- The information provided throughout the transplant process

- The quality of psychological/social support during the transplant process
- Healthcare after transplant
- The impacts of transplantation

1.3.4. Public health and wider societal impacts of transplantation

One of the aims of the group was to undertake a social care analysis report, looking at the impact of transplantation on society. This work was completed by the Scottish Government Health Analytical Services Division and assessed the evidence on the impact of transplantation on donor recipients, both in terms of long-term survival rates and effect on physiological and physical wellbeing. It is important to note that much of the available evidence is international and therefore findings may not be specific to the UK context. However, where possible, greater reliance was placed on systematic reviews and/or meta-analyses that attempt to synthesise the available evidence. To provide context, the paper first examines the demand for transplantation and the continuing challenges in increasing transplant rates and provides an overview of the demographic characteristics of donor recipients.

1.3.5. Health and social care resource impact analysis

This work was undertaken by the Scottish Government, with the goal to produce a health and social care economics analysis costing report, looking at the resource impact of the projected increase in transplant activity up to 2020. It examines transplantation from an economic, rather than financial, perspective, by applying financial valuations to the increases in the quantity and quality of life achieved (as measured by Quality Adjusted Life Years (QALYs)). It shows that the benefits accrued from the forecast transplant activity outweigh the costs.

2. Public health and wider societal impacts of transplantation

2.1. Demand for transplantation

As of 31 March 2014, there were 7,025 people on the UK transplant waiting list (just under 600 in Scotland). Though an increase in donation has led to this number steadily decreasing over the past five years, there is still a need for a continued increase in transplant activity.

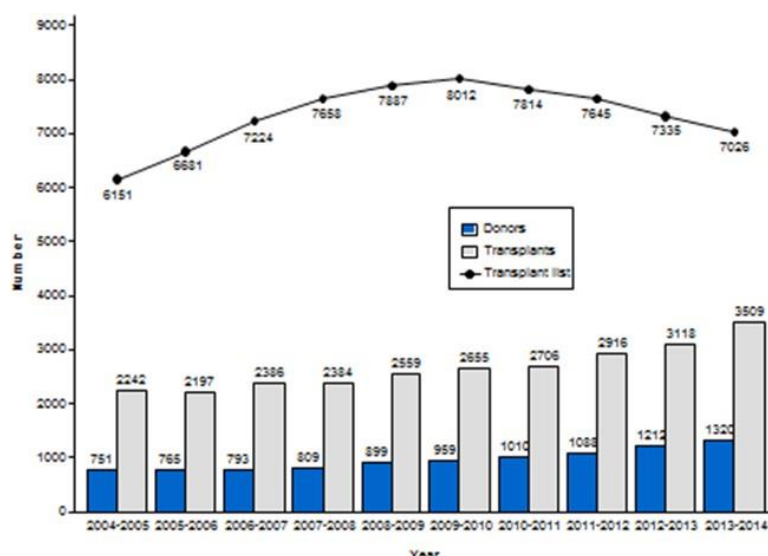


Figure 1 Number of deceased donors and transplants in the UK, April 2013 – March 2014, and patients on the active UK waiting list, end March 2014⁷

In 2013-14, 456 patients in the UK died whilst waiting for a transplant, while a further 828 were removed from the list, mostly as a result of deteriorating health or ineligibility for transplant.

The NHSBT Organ and Transplantation Activity Report 2013-14 found that:

- 19% of kidney patients had received a transplant within 1 year, while 35% were still waiting, had died, or had been removed from the transplant list 5 years later.
- Around two-thirds of liver patients received an organ within a year and almost three-quarters within 2 years.
- Less than half of non-urgent heart patients received a transplant within 3 years, while 43% died or were removed from the waiting list (due to deteriorating health).

There are a number of significant challenges experienced by individuals awaiting transplant, which include poor physical health, difficulties with employment, and restrictions in social life and daily activities.⁸ It has been shown that up to 50% of potential transplant recipients experience psychological issues, such as depression and anxiety.⁹ As a result, it is clear that

⁷ NHS Blood and Transplant (2014). Organ Donation and Transplantation: Activity Report 2013/14. Available from: http://www.organdonation.nhs.uk/statistics/transplant_activity_report/ [Accessed 22 January 2015].

⁸ Denny, B., & Kienhuis, M. (2011). Using crisis theory to explain the quality of life of organ transplant patients. *Progress in Transplantation*. 21(3), 182-188.

⁹ Olsbrich, M.E., et al. (2002). Psychological assessment and care of organ transplant patients. *Journal of Consulting and Clinical Psychology*. 70(3), 771-783.

continued increases in organ donation and transplantation would have significant positive impact on those on the transplant waiting list.

2.2. Demographics of transplant recipients

A specific issue has been identified among people in Black and Minority Ethnic (BME) communities, who are at greater risk of developing organ failure for a number of complex reasons, including genetic predisposition, increased prevalence of underlying conditions, and poorer access to and uptake of services.¹⁰ Furthermore, organ allocation is impacted by blood and tissue type, which tend to be closer when the donor and recipient have the same ethnicity. While all major religions either accept organ donation or accept the right of individuals to decide,¹¹ consent is considerably lower among BME communities. Overall, families of 40% of potential donors refuse consent at the critical time; this figure is 75% for potential donors from a BME background.¹²

Explicit recommendations to tackle the needs of the UK's multi-ethnic population have been developed by the UK Organ Donation Taskforce, which highlighted 'an urgent requirement to identify and implement the most effective methods through which organ donation and the "gift of life" can be promoted [...] specifically to the BME population'.¹³ Subsequently, NHSBT has run a campaign to address the critical shortage of organ donors from BME communities.

2.3. Impact of transplantation

2.3.1. Survival

At the basic level, patient survival is the principal outcome of transplantation. The table below shows 10 year patient survival rates for adult transplant recipients in the UK.

DBD	Kidney DCD	LD	Liver	Heart	Heart-lung	Lung
73%	67%	89%	62%	59%	36%	32%

Table 1 10 year patient survival rates for UK transplant recipients, 2000 – 2002¹⁴

Survival and socio-economic deprivation

One area of interest is the relationship between survival and socio-economic deprivation. There are three relevant UK studies which evaluate social deprivation in the context of kidney transplantation. Though these studies were limited by the number of patients involved, they do suggest that there may be an association between socio-economic deprivation and the long-term success of a kidney transplant.

West of Scotland ¹⁵	Wales ¹⁶	England ¹⁷
Social deprivation not associated with:	Socio-economic deprivation associated with:	Socio economic deprivation associated with:
Rate of living donor transplant	Higher rate of rejection	Increased mortality

¹⁰ Department of Health (2008). Organs for Transplants: A report from the Organ Donation Taskforce. Available from: <http://www.nhsbt.nhs.uk/to2020/resources/OrgansfortransplantsTheOrganDonorTaskForce1streport.pdf> [Accessed 21 January 2015].

¹¹ Bruzzone, P. (2008). Religious aspects of organ transplantation. *Transplant Proceedings*. 40(4), 1064-7.

¹² Department of Health (2008). Organs for Transplants: A report from the Organ Donation Taskforce.

¹³ Ibid.

¹⁴ NHS Blood and Transplant (2014). Organ Donation and Transplantation: Activity Report 2013/14.

¹⁵ Aitken, E., Dempster, N., & Ceresa, C. (2013). The impact of socioeconomic deprivation on outcomes following renal transplantation in the West of Scotland. *Transplantation Proceedings*. 45(6), 2176-2183.

¹⁶ Stephens, M.R., et al. (2010). The influence of socioeconomic deprivation on outcomes following renal transplantation in the United Kingdom. *American Journal of Transplantation*. 10(7), 1605-12.

¹⁷ Begaj, I., Khosla, S., & Ray, D. (2012). Impact of social deprivation on mortality 1-and 5-years post kidney transplantation in England over the last decade. *Transplantation*. 94(10S), 822.

- Graft/patient survival
- Graft survival

Table 2 Results of three UK studies on the relationship between patient/graft survival and socio-economic deprivation

2.3.2. Quality of life: Physical, psychological, and social health

In recent years, focus has not only been on survival but on the patient's long-term quality of life post-transplant. The term 'quality of life' refers to 'the physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person's experiences, beliefs, expectations, and perceptions'.¹⁸ There is a growing consensus regarding the need to consider a patient's opinions and experiences in the assessment of their health, alongside more traditional clinical outcomes.¹⁹ The following sections, therefore, describe the impact of transplantation on key domains of quality of life for transplant recipients.

Adolescents

With the increasing prevalence of paediatric transplantation, there is a need to better understand the psychological and social impacts of transplant on children, in order to inform interventional strategies and improve follow-up care for paediatric transplant recipients.

A number of challenges have been highlighted by adolescent transplant recipients:

Physical	Psychological	Social	Academic
• Medication side effects: ○ Short stature ○ Hair growth ○ Weight gain	• Self esteem • Anxiety about rejection and life of organ	• Parental overprotection • Interaction with peers	• Absenteeism due to poor health • Struggle to achieve results

Table 3 Challenges identified by adolescent transplant recipients²⁰

These types of challenges do affect the quality of life of adolescents who have received a transplant. On the whole, however, physical health and psychological development are significantly benefitted by transplantation, and transplant recipients tend to have a quality of life that is much higher than for those with end-stage organ disease.²¹

Adults: Kidney and pancreas

In evaluating quality of life for kidney transplant recipients, particular attention has been given to that of patients on dialysis, as an alternative to kidney transplant, which is not always a life-saving procedure (as for other organ transplants). Quality of life and psychological well-being do tend to be higher for transplant recipients than for either dialysis patients or pre-treatment patients.²²

Quality of life is also significantly improved for patients who receive simultaneous pancreas-kidney transplants for diabetes or end-stage renal disease. Despite some physical

¹⁸ World Health Organization (1991). *Quality of Life in Health Care*, Workshop, Geneva, Switzerland, 11-16 February 1991.

¹⁹ Burra, P., & De Bona, P. (2007). Quality of life following organ transplantation. *Transplant International*. 20(5), 397–409.

²⁰ Tong, A., et al. (2009). Adolescent Experiences Following Organ Transplantation: A Systematic Review of Qualitative Studies. *Journal of Pediatrics*. 155(4), 542-9.

²¹ Rubik, J., et al. (2000). [Quality of life in children and adolescent with end-stage renal disease treated with dialysis and kidney transplantation]. *Polski Merkuriusz Lekarski*. 8(46), 280-1; Avitzur, Y., et al. (2004). Health status ten years after pediatric liver transplantation - looking beyond the graft. *Transplantation*. 78(4), 566; Taylor, R., et al. (2005). A critical review of the health-related quality of life of children and adolescents after liver transplantation. *Liver Transplantation*. 11(1), 51-60.

²² Wyld, M., et al. (2012). A systematic review and meta-analysis of utility-based quality of life in chronic kidney disease treatments. *PLOS Medicine*. 9(9), e1001307; Cameron, J.I., et al. (2000). Differences in quality of life across renal replacement therapies: a meta-analytic comparison. *American Journal of Kidney Disease*. 35(4), 629-37.

challenges (such as medication side effects), there tends to be overall benefit for transplant recipients in terms of physical health, social interactions, and increased energy.²³

Adults: Liver

Liver transplant has been found to have specific long-term improvements in quality of life, despite some negative side effects from original liver disease and the immunosuppressant regime. Though quality of life tends not to be quite as high as that of the general population, it is significantly improved upon that of pre-transplant patients.²⁴ Particular areas of improvement for liver transplant recipients include physical function, mental health, social functioning, and ability to return to a normal lifestyle.²⁵

Adults: Heart

Heart transplant has been found to have a more dramatic impact on quality of life than other organ transplants, with a significant overall improvement seen immediately after the operation.²⁶ There are also a number of long-term improvements that can be seen in various dimensions: physical (mobility, home management, eating, body care, sleep), social (interaction, recreation, pastimes), and psychological (depression, emotion).²⁷

After receiving a heart transplant, the factors that seem to affect quality of life are primarily psychological and include stress level, perception of health, effectiveness of coping strategies, and information provision from healthcare workers.²⁸ It follows, therefore, that psychological well-being (and quality of life) for transplant recipients could be improved through 'enhancing perceived control over health and daily life, promoting an optimistic outlook by facilitating access to social support from other heart transplant recipients and ensuring post-transplant recipient-caregiver partnerships adequately support the transition back to independence'.²⁹

Adults: Lung

Lung transplant results in significant clinical improvements for patients with advanced lung disease, who experience impairments in physical and mental wellbeing pre-transplant. The particular areas which experience the greatest improvement tend to be in physical health and functioning. It has been suggested that transplant results in a greater benefit to quality of life for lung recipients than for other organs, as a result of the severely poor health of potential lung transplant patients.³⁰

When considering the psychological wellbeing of lung recipients, the most important influencing factors tend to be psychiatric history, educational level, and post-transplant

²³ Burra & De Bona (2007).

²⁴ Yang, L.S., et al. (2014). Liver transplantation: a systematic review of long-term quality of life. *Liver International*. 34(9), 1298-313.

²⁵ Tome, S., et al. (2008). Quality of life after liver transplantation. A systematic review. *Journal of Hepatology*. 48(4), 567-77.

²⁶ Lough, M.E., et al. (1985). Life satisfaction following heart transplantation. *Journal of Heart Transplantation*. 4(4), 446-9; Bunzel, B., et al. (1991). Quality of life after orthotopic heart transplantation. *Journal of Heart and Lung Transplantation*. 10(3), 455-9.

²⁷ Fisher, D.C., et al. (1995). Changes in health-related quality of life and depression in heart transplant recipients. *Journal of Heart and Lung Transplantation*. 14(2), 373.

²⁸ Grady, K.L., Jalowiec, A., & White-Williams, C. (1999). Predictors of quality of life in patients at one year after heart transplantation. *Journal of Heart and Lung Transplantation*. 18(3), 202-10.

²⁹ Conway, A., et al. (2013). The psychological experiences of adult heart transplant recipients: a systematic review and meta-summary of qualitative findings. *Heart Lung*. 42(6), 449-55.

³⁰ Singer, J.P., et al. (2013). Thematic analysis of quality of life in lung transplant: the existing evidence and implications for future directions. *American Journal of Transplantation*. 13(4), 839-50.

support.³¹ This reiterates the importance of ensuring support is available to transplant patients, both before and after their operation.

2.3.3. Quality of life: Specific domains

Employment

An important goal of transplantation is to enable people to return to work. Improved employment outcomes can positively contribute to a transplant recipient's identity, self-esteem, and quality of life, as well as benefiting society as a whole. Detailed information on transplant recipients' employment is limited, but the results tend to be positive. It has been reported that approximately 80% of organ transplant recipients in developed Western Europe are able to return to full-time employment after a successful operation.³²

Factors associated with return to employment: ³³	
Physical health	• Functional ability • Number of rejection episodes • Time on waiting list
Socio-economic	• Education level • Previous employment • Time spent off work

Table 4 Factors associated with a return to employment for transplant recipients

Sexual function

One factor significantly impacting quality of life in people with end-stage organ disease is sexual dysfunction. Erectile dysfunction has been reported as high as 70%, while influencing factors include age, nutrition, diabetes, and severity of disease.³⁴ Whilst evidence can be contradictory, transplantation does tend to be beneficial in this area. A survey of sexual concerns involving 768 transplant recipients indicated that transplantation has a positive impact on sexuality, with only 26% of respondents not being sexually active.³⁵

Pregnancy

For women with end-stage organ disease, organ transplant is the best option for pregnancy, with over 70% of US post-transplant pregnancies successfully resulting in birth.³⁶ Some complications have been seen in pregnant women who have received a transplant; these include pre-eclampsia and preterm birth, but not congenital malformations.³⁷ The chances for a successful pregnancy are overall much stronger for transplant recipients than those with end-stage organ disease.

Family relationships

Another significant factor in quality of life concerns family relationships, particularly within the family. This is especially relevant for living donor transplants, which are often between family

³¹ Burra & De Bona (2007).

³² Slapak, M. (2005). Sport and transplantation. *Annals of Transplantation*. 10(1), 62.

³³ Petrucci, L., et al. (2007). Return to work after thoracic organ transplantation in a clinically-stable population. *European Journal of Heart Failure*. 9(11), 1112-9; Knight, R.J., & Daly, L. (2004). The impact of pancreas transplantation on patient employment opportunities. *Clinical Transplantation*. 18(1), 49-52.

³⁴ Toda, K., et al. (2005). Erectile dysfunction in patients with chronic viral liver disease: its relevance to protein malnutrition. *Journal of Gastroenterology*. 40(9), 894-900; Greenstein, A., et al. (1997). Does severity of ischemic coronary disease correlate with erectile function? *International Journal of Impotence Research*. 9(3), 123-6.

³⁵ Hart, L.K., et al. (1997). Survey of sexual concerns among organ transplant recipients. *Journal of Transplant Coordination*. 7(2), 82-7.

³⁶ Sivaraman, P. (2004). Management of pregnancy in transplant recipients. *Transplantation Proceedings*. 36(7), 1999-2000.

³⁷ Källén, B., et al. (2005). Pregnancy outcome after maternal organ transplantation in Sweden. *BJOG*. 112(7), 904-9.

members. A donor's relationships with their family tend to be strengthened, rather than harmed, after a transplant.³⁸ There have been, however, instances in which children who received a transplanted organ from a parent felt some distress and isolation, as a result of feelings of obligation or reciprocity.³⁹ This shows the need to ensure adequate support is in place, not only for paediatric recipients, but also for their parents and/or carers.

Education and schooling

As the numbers of paediatric transplant recipients continue to increase, attention has begun to focus on the long-term effects of receiving a transplant on an individual. This includes their education, as up to 40% of chronically ill children experience difficulties at school, both academically and socially.⁴⁰

Table 5 summarises the results of a number of studies to examine the academic attendance of children who have received organ transplants. As it shows, a significant number are able to return to school as normal, following a successful transplant.

Kidney	Liver
93% in school⁴¹ 86% in full-time school⁴²	79% in school 69% experienced no delay in education⁴³ 89% in full-time school⁴⁴

Table 5 Literature results on the return to schooling of adolescent transplant recipients

Sport participation

Prior to receiving an organ transplant, the physical health of patients tends to generally be quite poor, preventing them from participating in certain social activities, such as sport and exercise. Though transplant recipients do still have different reactions to physical activity than the health population,⁴⁵ research tends to show that they are much more able to participate in these activities post-transplant. This is the case for both adults⁴⁶ and children.⁴⁷

2.3.4. Quality of life: Living donors

While most studies focus on the quality of life of transplant recipients, it is also important to consider that of living donors. It is encouraging to see that living kidney donors tend to report increased self-esteem, along with no regrets.⁴⁸ Furthermore, quality of life tends to be positive, regardless of the outcome of the transplant.⁴⁹

There are similarly positive results for live liver donors, which is reassuring since live liver donation is a more controversial procedure, due to the higher risk to donor.⁵⁰ Despite a decline in physical health, live liver donors generally reported a high quality of life.⁵¹ There

³⁸ Clemens, K.K., et al. (2006). Psychosocial health of living kidney donors: a systematic review. *American Journal of Transplantation*. 6(12), 2965-77.

³⁹ Franklin, P.M., & Crombie, A.K. (2003). Live related renal transplantation: psychological, social, and cultural issues. *Transplantation*. 76(8), 1247-52.

⁴⁰ Burra & De Bona (2007).

⁴¹ Englund, M., Berg, U., & Tyden, G. (2003). A longitudinal study of children who received renal transplants 10-20 years ago. *Transplantation*. 76(2), 311-8.

⁴² Uddin, G.M., & Hodson, E.M. (2004). Renal transplantation: experience in Australia. *Indian Journal of Pediatrics*. 71(2), 137-40.

⁴³ Fouquet, V., et al. (2005). Long-term outcome of pediatric liver transplantation for biliary atresia: 10-year follow-up in a single center. *Liver Transplantation*. 11(2), 152-60.

⁴⁴ SPLIT Research Group. (2001). Studies of Pediatric Liver Transplantation (SPLIT): year 2000 outcomes. *Transplantation*. 72(3), 463-76.

⁴⁵ Burra & De Bona (2007).

⁴⁶ Kjær, M., Beyer, N., & Secher, N.H. (1999). Exercise and organ transplantation. *Scandinavian Journal of Medicine & Science in Sports*. 9(1), 1-14.

⁴⁷ Daudet, G., Dupuis, J.M., Jockey-Monrozier, D., Reix, P., Cochat, P., & Bellon, G. (2005). [Kidney transplanted child and sport practices]. *Archives de Pédiatrie*. 12(3), 273-7.

⁴⁸ Franklin & Crombie (2003).

⁴⁹ Clemens, K., et al. (2011). The long-term quality of life of living kidney donors: a multicenter cohort study. *American Journal of Transplantation*. 11(3), 463-9.

⁵⁰ Rudow, D.L., et al. (2005). Kidney and liver living donors: a comparison of experiences. *Progress in Transplantation*. 15(2), 185-91; Parolin, M.B., et al.

(2004). Donor quality of life after living donor liver transplantation. *Transplantation Proceedings*. 36(4), 912-3.

⁵¹ Walter, M., et al. (2003). Quality of life of living donors before and after living donor liver transplantation. *Transplantation Proceedings*. 35(8), 2961-3.

have been, however, some donors who had poor psychosocial outcomes, which could be mitigated by the presence of stronger social and psychological support.⁵²

3. Quality

3.1. Existing quality indicators

A significant amount of data is collected and submitted by all transplantation services for the purposes of clinical audit. For transplantation, the majority of reported quality indicators relate to survival based indicators for the transplant recipient and the graft transplanted.

The quality indicator dashboard below shows a Red Amber Green (RAG) status for each quality indicator. A red status represents significant concerns, an amber status indicates that some improvement is required, and a green status indicates that there are no concerns. All concerns outlined are in the process of being addressed by the service and the commissioner as part of the commissioning cycle. Detailed data on these quality indicators is included within appendix 1.

Service	Indicator	Comments	RAG
Adult heart transplantation (Golden Jubilee National Hospital)	Risk-adjusted 30 day, 1 year, 3 year and 5 year patient survival post-transplant	-	G
	1 year, 5 year and 10 year patient survival from listing	-	G
	Heart offer decline rates that resulted in a transplant	-	G
	Median cold ischaemia time in adult DBD donor heart transplants	-	
	Incidence of transplants by NHS Board of residence	NHS Highland below expected range	A
Adult heart transplantation (Freeman Hospital, Newcastle)	Risk-adjusted 30 day, 1 year, 3 year and 5 year patient survival post-transplant	-	G
	1 year, 5 year and 10 year patient survival from listing	Lower than UK average, however, complex ACHD case mix	G
	Heart offer decline rates that resulted in a transplant	Higher than expected range	A
	Median total ischaemia time in adult DBD donor heart transplants	-	
Paediatric heart transplantation (Freeman Hospital and Great Ormond Street)	30 day, 1 year, 3 year and 5 year patient survival after first transplant	-	G
	Median cold ischaemia time in paediatric DBD donor heart transplants	-	
Adult lung transplantation (Freeman Hospital, Newcastle)	Risk-adjusted 90 day, 1 year, 3 year and 5 year patient survival post-transplant	-	G
	1 year, 5 year and 10 year patient survival from listing	-	G
	Lung offer decline rates that result in a transplant	Significantly low bilateral lung offer decline rate	G
	Median cold ischaemia time in adult DBD donor lung transplants	-	
	Incidence of transplants by NHS Board of residence	NHS Fife and NHS Lanarkshire, significantly below the Scottish average	A

⁵² Clemens, K.K., et al. (2006); Burra & De Bona (2007).

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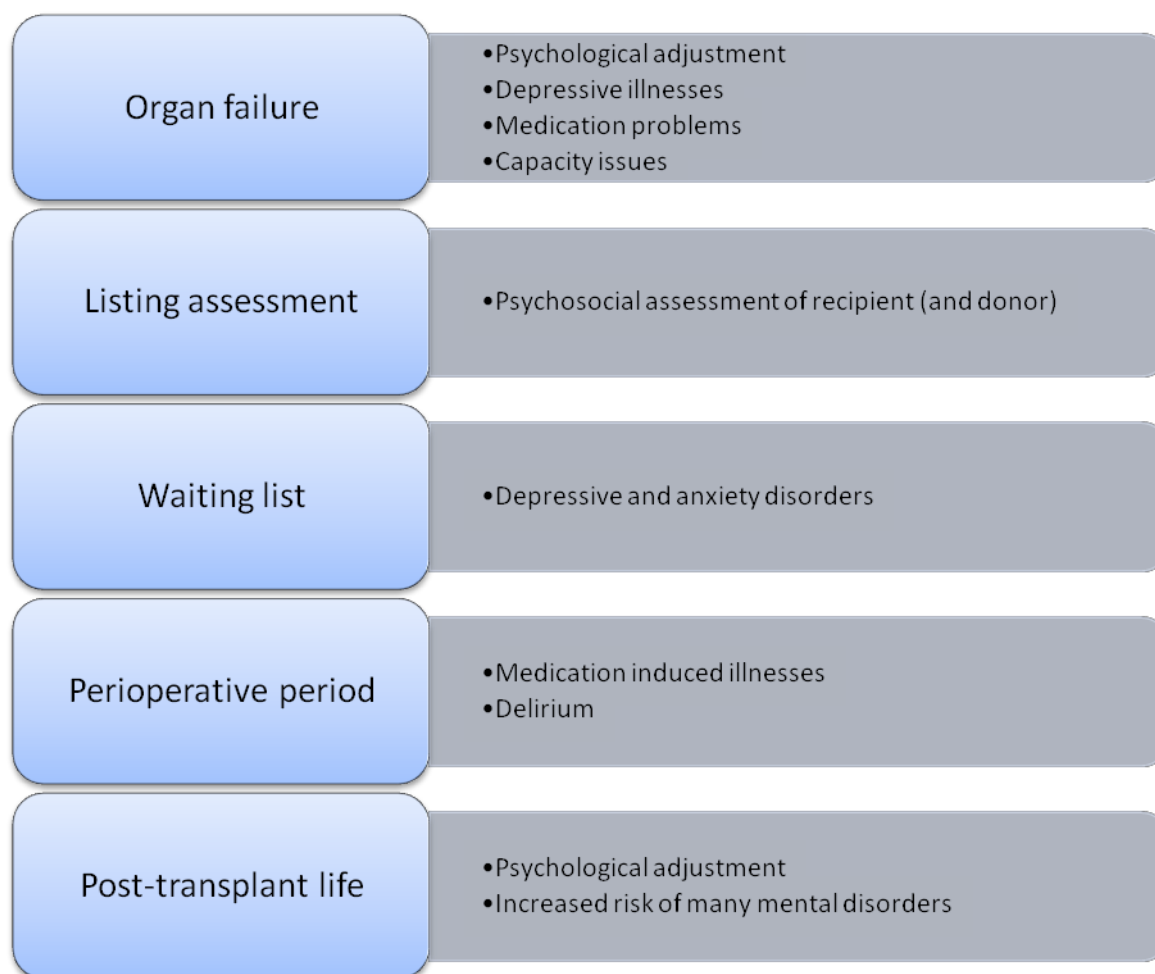
		in 2013/14	
Paediatric lung transplantation (Freeman Hospital and Great Ormond Street)	90 day, 1 year, 3 year and 5 year patient survival after first transplant	-	G
Adult kidney transplantation (Western Infirmary Glasgow and Royal Infirmary of Edinburgh)	Risk-adjusted 1 year, 5 year and 10 year patient survival post-transplant (deceased and living donors)	-	G
	Risk-adjusted 1 year, 5 year and 10 year graft survival post-transplant (deceased and living donors)	-	G
	Pre-emptive listing and transplant rates (deceased and living donors)	-	A
	Kidney offer decline rates that result in a transplant	Glasgow lower than expected range	G
	Median cold ischaemia time (DBD, DCD and living donors)		
	Estimated Glomerular Filtration Rate (DBD, DCD and living donors)	-	G
	Geographical access (deceased and living donors)	-	G
Paediatric kidney transplantation (Royal Hospital for Sick Children Glasgow)	Risk-adjusted 1 year and 5 year patient survival post-transplant	-	G
	Risk-adjusted 1 year and 5 year graft survival post-transplant	-	G
	Pre-emptive listing and transplant rates (deceased and living donors)	-	A
	Paediatric kidney offer decline rates that result in transplant	-	G
	Incidence of transplants by NHS Board of residence		G
Simultaneous kidney-pancreas and pancreas-alone transplantation (Royal Infirmary of Edinburgh)	Patient and graft survival at 1 and 5 years post-transplant	-	G
	Pancreas offer decline rates that result in a transplant	Higher than expected range	A
	Median cold ischaemia time in DBD donor pancreas transplants	-	
	Incidence of transplants by NHS Board of residence	NHS Forth Valley and NHS Highland significantly below the Scottish average in 2013-14	A
Islet transplantation (Royal Infirmary of Edinburgh)	Patient survival	-	G
	Islet offer decline rates	-	G
	Incidence of transplants by NHS Board of residence	-	G
Adult liver transplantation (Royal Infirmary of Edinburgh)	90 day patient survival for both adult elective and super urgent first liver transplants	-	G
	90 day graft survival for both adult elective and super urgent first liver transplants	-	G
	Observed risk-adjusted 1 year, 3 year and 5 year patient survival rates for both adult elective and super urgent first liver transplants	-	G
	Median cold ischaemia times for adult DBD and DCD liver transplants	-	G
	Incidence of transplants by NHS Board of residence	NHS Ayrshire and Arran significantly below the Scottish average in 2013-14	A
Paediatric liver transplantation (Birmingham, King's College and Leeds)	90 day patient and graft survival for paediatric first liver transplants	-	G
	One year unadjusted patient survival for paediatric elective first transplants and super urgent first transplants	-	G
	Observed unadjusted 1 year, 3 year and 5 year patient survival rates for both paediatric elective and super urgent first liver transplants	-	G

	Median cold ischaemia times for paediatric DBD and DCD liver transplants	-	
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Table 6 Quality indicator dashboard

3.2. Transplant psychiatry

Psychiatric assessment, support, and intervention is often valuable for transplant recipients and live donors. The following chart illustrates the rationale for psychiatric involvement at various stages in the transplant pathway. This information was provided by the Department of Psychological Medicine at the Royal Infirmary of Edinburgh.



It is important to recognise that psychiatry is needed as a medical speciality distinct from psychological support. The psychiatrist is required to explore a number of potential risks and requirements for intervention before advising that the individual is able to proceed with transplant.

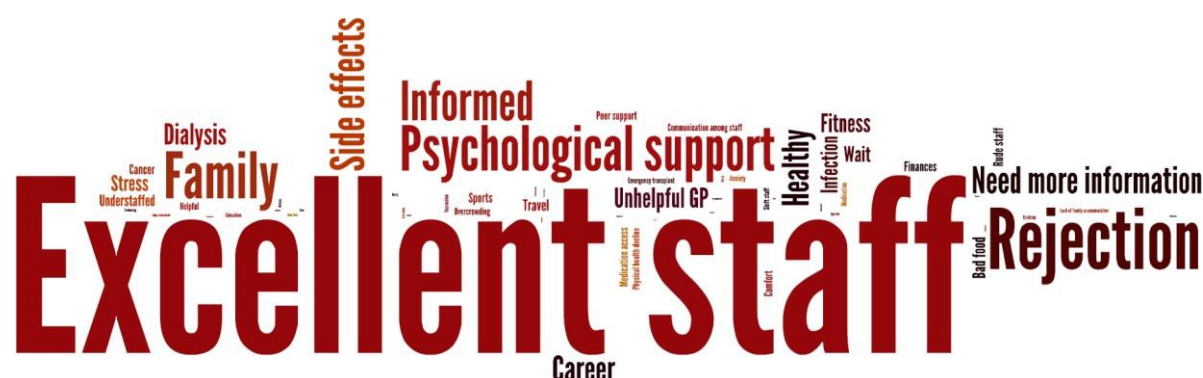
After the Human Tissue Authority (HTA) approved altruistic donation in 2006, they introduced a requirement for a formalised mental health review of potential donors. This requirement has now been withdrawn but is still recommended by BTS and NHSBT. The HTA also introduced independent assessment of the donor. This non-psychiatric assessment is undertaken in order to ensure that the donor has capacity, is prepared for the consequences, and is not subject to duress, coercion or incentive.

Patient survey

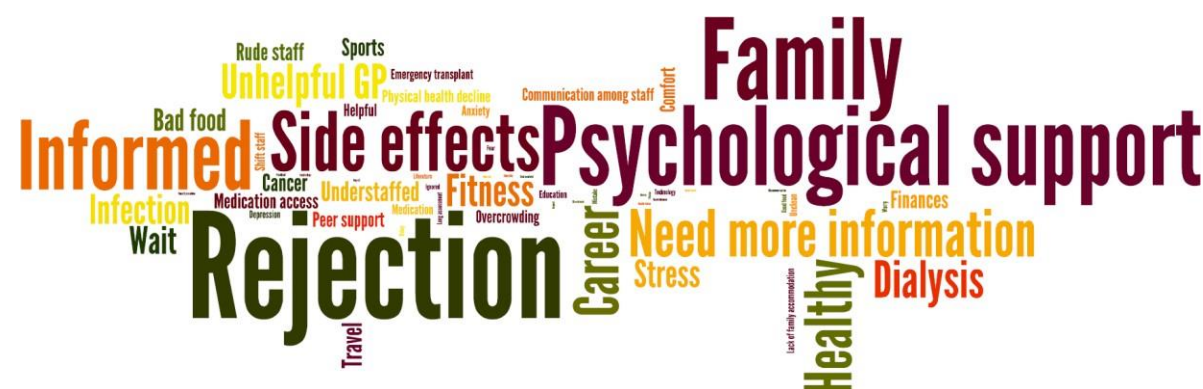
A total of 134 completed questionnaire responses were received. Respondent demographics are outlined in Appendix 2.

On the whole, patient experience of the national transplant services was very positive, with 91% of respondents indicating that they were satisfied or very satisfied with the transplant unit. A number of themes emerged from the responses, relating to all areas of the transplant pathway. These themes are summarised below.

The following word clouds display the various themes that emerged in the questionnaire, with the size of each theme being proportional to the number of instances where a theme was highlighted by the responses.



There was such high praise for the staff in the transplant units, that a second word cloud was created with the 'Excellent staff' theme removed in order to better show the other themes highlighted.



Key themes at each stage of the patient pathway

The questionnaire was structured to identify themes throughout the pathway of a transplant recipient. Key themes from the questionnaire are summarised in the figure below.

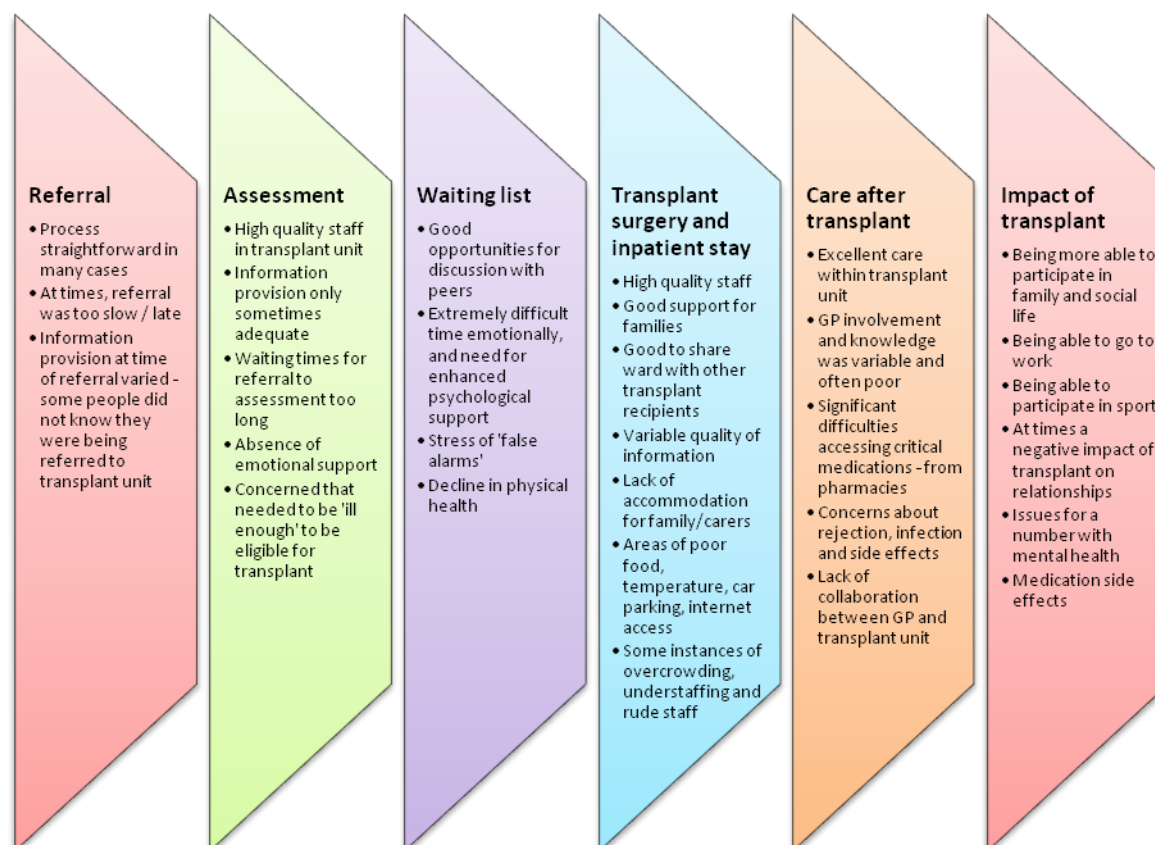


Figure 2 Key themes outlined in the responses to the transplant recipient questionnaire

Focus groups

The focus groups were structured to provide further detail on key themes from the questionnaire and throughout the pathway of a transplant recipient. Detail from these responses is provided below, with key themes outlined in bullet points.

Detailed responses

Detailed responses from the patient questionnaire and focus groups are outlined in the sections below.

Referral process

Questionnaire feedback

Positive areas

- The process was generally felt to be straightforward and efficient by the majority of respondents.

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Variable areas

- 85% of respondents felt they were referred at the right time, but 10% felt they should have been referred earlier, and 5% were unsure.
- While a number of people felt that they were fully informed at this stage in the process, others indicated that more information would have been helpful.

Negative areas

There were several administrative errors during the referral process. In one instance, paperwork was misfiled, and another person indicated that their blood samples were misplaced between the transplant unit and local hospital.

Focus group feedback

Key themes from the patient focus groups are outlined below:

Information provided and timeliness

- Some not told that they were referred for a transplant assessment.
- A number of recipients felt that there were delays in the referral process.

A lack of information during the referral process was seen to be a concerning issue, as a number of participants indicated that they did not even realise they were being referred for transplant assessment.

Assessment

Questionnaire feedback

The chart below indicates that the majority of people who responded to the questionnaire (93%) were satisfied with the care provided by the transplant team during their assessment for transplant.

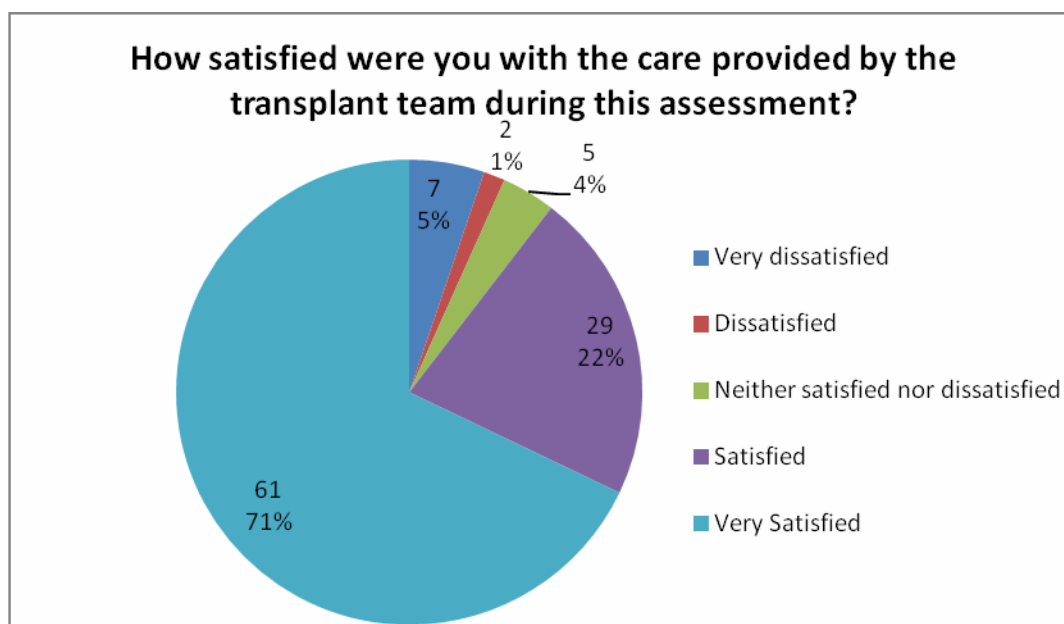


Figure 3 Satisfaction with the assessment process

Positive areas

- The staff within the transplant unit undertaking the assessment were generally felt to provide a high quality, helpful and informative service.

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Variable areas

- In relation to the information provided during the assessment process, some people thought that this was very good and felt that they were fully informed. Others, however, indicated that they did not feel they received sufficient information, with the suggestion that more information for relatives would have been especially helpful.

Negative areas

- Some indicated that waiting times, both from referral to assessment, and on the day of the assessment, were felt to be too long.
- It was suggested that a booklet on the thoughts and fears associated with waiting for transplant (similar to those provided for practical and medical issues) was lacking and would be a helpful addition.
- The assessment period was noted as stressful, with patients knowing that they need to be 'unwell enough' in some areas, but at the same time sufficiently well in others to be eligible for transplant.

One person felt that there was discrimination against people with a high BMI, especially when exercise was difficult due to a decline in health.

Focus group feedback

Key themes relating to assessment from the patient focus groups are outlined below:

Information provided

- Some information is currently available in booklet form.
- Several indicated that there is a lack of information:
 - In advance of assessment.
 - Regarding how decisions are made.
- People experienced varied amounts of involvement in decision making.
- Important for family / carer to attend as too much information to take in alone.

A number of participants felt that they were given adequate information during the assessment through booklets and conversation with the consultants. Though several of them expressed that there was not much of a decision to be made (transplant was necessary to live), they still felt involved in the conversation.

Several participants, however, expressed dissatisfaction regarding information provided in advance of the assessment. One participant described the process as 'terrifying – lack of understanding over this, i.e. not an exam with pass or fail'.

It was also felt that the reasons for whether or not to put someone on the list were unclear and sometimes unfair: 'Nobody lets you know that you sometimes have to challenge decisions and actually fight your case'.

Psychological impact

- Support would be helpful when first told about the need for transplant.
- Assessment week could be very confusing and overwhelming.
- Devastating experience for those not accepted onto list.

Some participants felt that they were offered opportunity to talk over worries and concerns with the coordinator or consultant. The assessment process was felt to be very emotionally

draining, not only for the patient, but also for their family / carers. As one participant shared, 'Partners and family tend to be left in the lurch after the diagnosis.'

Waiting list

Questionnaire feedback

The chart below indicates that the 89% of questionnaire respondents felt that they received sufficient support for their healthcare needs whilst on the transplant waiting list. 23% of respondents felt that they did not have sufficient support for their emotional needs whilst on the waiting list, with a further 15% uncertain about whether this was the case. A quarter of respondents indicated that their relatives did not have sufficient support for their emotional needs during this period.

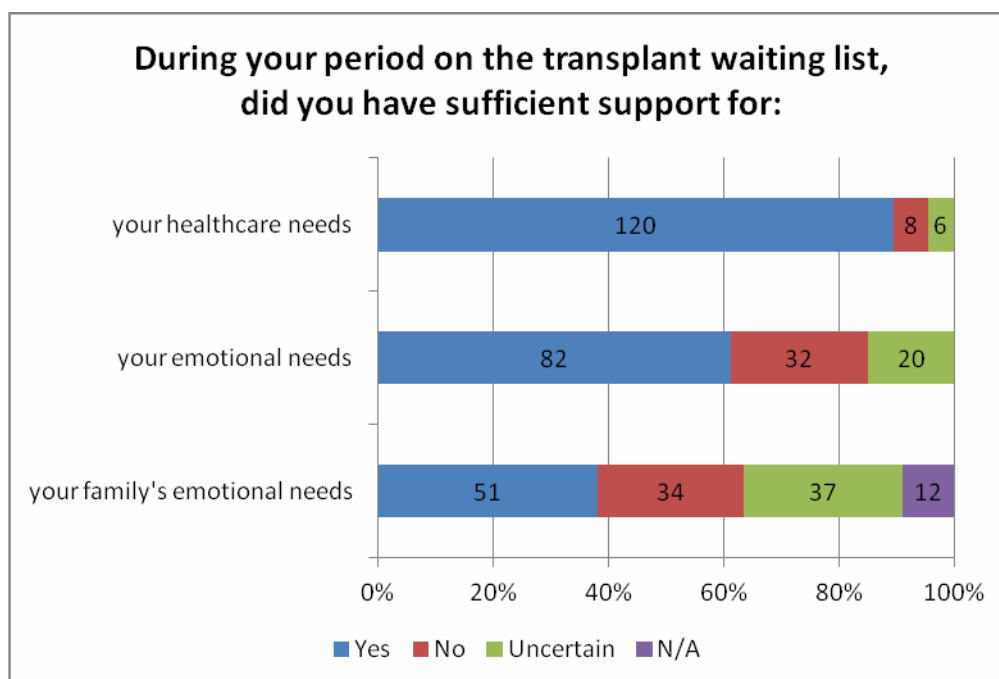


Figure 4 Support for recipients whilst on the transplant list

Positive areas

- The opportunity to speak with people who had received transplants whilst on the waiting list was felt to be very beneficial, and this was promoted by some transplant services.

Negative areas

- Fourteen people suggested that there was a need for psychological support, emphasising the emotional turmoil of being on the waiting list: 'This period I feel was hard to get it together in my head thinking that someone had to die to allow you to get your transplant'.
- Several respondents emphasised the stress and frustration caused by ('false alarm') calls that didn't result in transplant, with one person stating: 'I did not know that when I got "the call" for the transplant that I wasn't the only one. People should be made aware that if you get a call it doesn't mean that you are definitely getting a transplant.'

Decline in physical health was also a concern whilst on the waiting list. One person wound up on dialysis because it took too long to receive a transplant. Another mentioned the difficulty in keeping fit while on dialysis, without financial support.

Focus group feedback

Key themes relating to the waiting list from the patient focus groups are outlined below:

Information received

- There was desire to receive more information about:
 - Where one is on list / how the list works.
 - That / why false alarm calls happen.
- One-on-one support would be preferred to a group session.
- There were feelings of being left alone to find information.
- Should be information about importance of taking medication.

Participants felt there were two areas about which there should be more information while on the waiting list:

1. Knowing where one is on the waiting list (and even that one is still on the list – one person waited nine years and at times, especially after starting dialysis, was not always sure if they were still on the list).
2. Participants felt strongly that more information should be given about 'false alarms': when one is called about an organ becoming available but the operation is delayed or cancelled. It was understood that this is sometimes necessary, but advance warning that this could happen would have been appreciated.

Psychological impact

- Participants expressed feelings of abandonment.
- Difficulty dealing with where organ comes from.
- A patient support group would be helpful.
- Difficulty in asking family members to donate kidney.
- One person was phoned by Macmillan offering assistance in sorting out financial claims.

There were strong feelings of abandonment during this stage of the transplant pathway: 'You are put on a list and forgotten about'. Time on the waiting list was felt to be incredibly stressful, dealing with the decline in physical health, the knowledge of where the organ needed to come from, and the potentially long wait. One person said, 'When I got the call saying there was an organ available, it was a shock – I didn't think it was real'.

Other issues

One participant was an inpatient in their local hospital while waiting for an organ to become available. One night, they heard the phone ringing at the nurse's station but no one answered. Eventually, it turned out to be the call that an organ was available. This participant wondered what would have happened if no one had ever picked up the phone and suggested that there should be stronger emphasis on waiting for the call.

Another participant shared that they were asked to detour to another hospital to pick up their notes before heading to the hospital for transplant surgery.

Transplant surgery and inpatient stay

Questionnaire feedback

The charts below indicate the levels of satisfaction that questionnaire respondents expressed regarding the care and information received during their inpatient stay after receiving their transplant. 89% were satisfied with the care they received during their inpatient admission, and 89% were satisfied with the information received during this period.

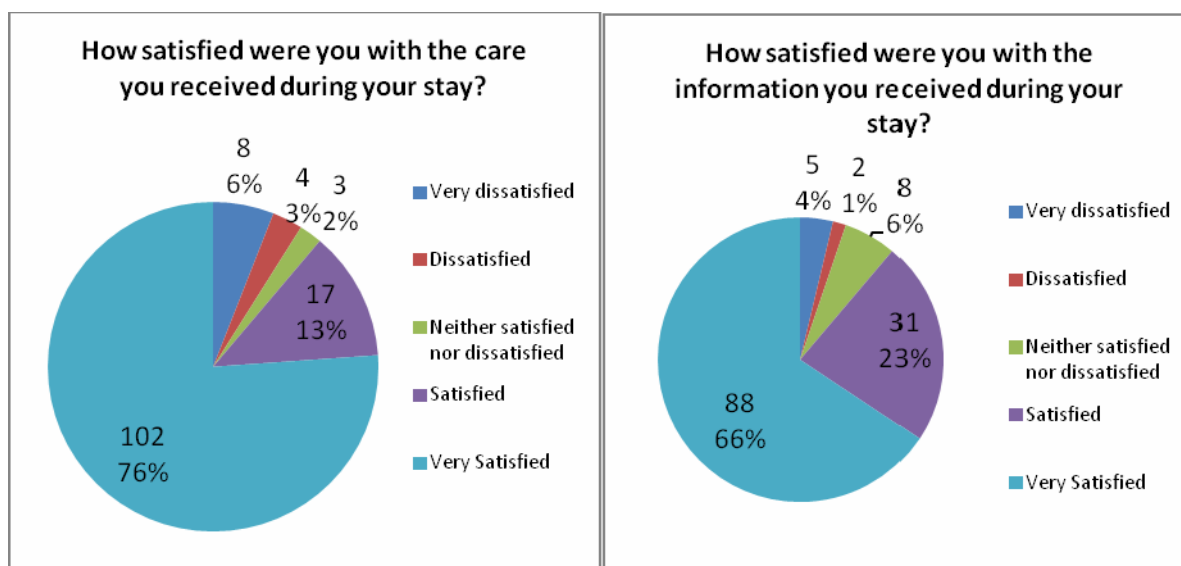


Figure 5 Transplant recipient satisfaction with the care received during inpatient stay

Figure 6 Transplant recipient satisfaction with the information received during inpatient stay

Positive areas

- The majority of responses (100+) indicated that one of the best things about the transplant unit was the quality of staff and healthcare received. There was praise for all members of staff, from the cleaners to nurses to doctors. Staff were described as professional, knowledgeable, caring, and friendly.
- In response to the question, 'From your point of view, what could have been done better?' twenty-nine people indicated 'nothing' or that everything was 'brilliant'.
- A number of people expressed gratitude that the staff were supportive and helpful, not only to the patients but also to their families.
- A shared ward with other transplant recipients was felt to be beneficial to morale.

Variable areas

- Whilst the majority were satisfied with the information they received, views about the quality of information received were variable, with thirty-two people indicating that they received good information. Thirteen respondents did, however, feel that more information should have been given, particularly about medications and life after transplant.
- Food choices in hospital were generally felt to be poor; reasons include inadequate catering for special diets and meals with insufficient calories for someone battling infection. Two people did, however, note that the food offered in hospital was good.

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Negative areas

- There were some issues with understaffing and rude or unknowledgeable staff, usually related to staff at weekends or at night.
- Respondents who had been boarded to other wards due to overcrowding felt that care was poorer in other wards as the staff were not as well equipped to deal with transplant recipients.
- Several comfort issues were commented upon, including poor internet access, temperatures being too hot, having to pay for parking and television, and the cleanliness of toilet and shower areas.
- There was felt to be a lack of reasonably priced accommodation for family members.

Focus group feedback

Key themes relating to transplant surgery and the inpatient stay of patient focus groups participants are outlined below:

Information

- Most staff in the transplant unit were noted as being of high quality, and the role of the Transplant Coordinator was often emphasised.
- Talking with another transplant recipient was very helpful.
- So much emphasis on surgery that the patient is often not prepared for next stage:
 - Side effects of medications not always adequately explained.
 - Unrealistic expectations given for return to work.

Overall, participants praised the staff in the transplant units. They particularly appreciated the knowledge that staff within the unit had about transplants. It was felt that nurses in the transplant wards really cared, but understaffing at times had an impact. A number of participants felt that the transplant coordinator was especially helpful, though others did not. One participant shared that one of the most reassuring interactions came through a conversation with someone who had already been through the process.

Though one participant expressed that they had received information through booklets about what to expect after transplant, a number of others stated that they felt unprepared for the next stage in life, particularly what to expect regarding the side effects of drugs. It was felt that clinicians could sometimes be so focused on medical issues that they neglected to fully inform the patient about these other issues.

Psychological impact

- Not all patients offered psychological support.
- Support in children's services but not adult.
- Clinicians sometimes felt to be lacking in people skills / sensitivity.
- Family members need support:
 - Only two named individuals allowed to visit ward.
 - Family left unattended, with nowhere to stay, during surgery.
 - Lack of financial support.
- Could use a 'Maggie's Centre' for transplant patients.

One of the themes raised was the psychological effect of the whole process on family and carers. A number of participants mentioned that their family was given no support throughout the process and left unattended during the surgery, with no updates or even a place to go.

One participant expressed gratitude for the psychological care and support received at the Golden Jubilee National Hospital, then commented that 'we should expect that level of professionalism from all hospitals'.

Other issues

- Concerns about bed availability were noted in certain hospitals.
- Respondents were concerned about infection when they were placed in wards of 4 beds. A number felt that transplant patients should be in single rooms to protect against infection.
- Food provided was not always what was ordered.

Impact of having a transplant on the recipient's life

Questionnaire feedback

Positive areas

- Thirty-two people mentioned the positive effect that the health benefits of receiving a transplant had on their family, including the opportunities to get married, have children, or simply 'lead a normal family life'.
- Receiving a transplant provides opportunities that were sometimes unavailable (or more difficult) beforehand. Fourteen people mentioned greater freedom now that they were no longer on dialysis. Twenty-two people were able to return to work or start a career, four people were able to pursue education, and ten mentioned involvement in sports and exercise.

Variable areas

- The effect that receiving a transplant had on people's mental health varied. Twenty-eight people mentioned that they were now stronger emotionally, but eighteen emphasised the anxiety and depression with which they currently struggle.

Negative areas

Twelve people mentioned the negative impact of side effects from their medication, including appearance, emotions, headaches, and greater susceptibility to illness. This was an area about which some felt they had not been adequately informed.

Focus group feedback

Key themes relating to the impact of receiving a transplant on the lives of patient focus groups participants are outlined below:

- Being alive and getting life back.
- Being in better health than before the transplant.
- Being able to be physically active and participate in sport:
 - A number of people indicated that they had competed in the Transplant Games.
- Being able to return to work, start in new employment, or pursue further education:
 - Some people had difficulties in returning to employment due to time spent off sick and/or perceptions by future employers of the ability of transplant recipients to fully contribute in the workplace.
- Changes to everyday life:

- Changes in interpersonal relationships as a result of the transplant and the need to stay well.
- Keeping well takes up a lot of time (e.g. exercise, sleeping, eating well, psychological health, medications).
- Side effects caused by transplantation, such as fertility issues.
- Psychological effects – much more emotional than before.
- No longer being viewed as the 'sick person':
 - This was seen both from positive and negative perspectives, with some indicating that those around them expected them to be cured, and others indicating that it was positive to not be labelled as the 'sick person' – exchange of symptoms.
- Issues with accessing insurance for holidays.
- Issues with accessing state benefits (e.g. Disability Living Allowance).

One issue raised by a number of participants involved transplant being seen 'as a cure' by others, including family, friends, and employers. A related issue was being taken off Disability Living Allowance (DLA) after transplant, despite remaining health problems.

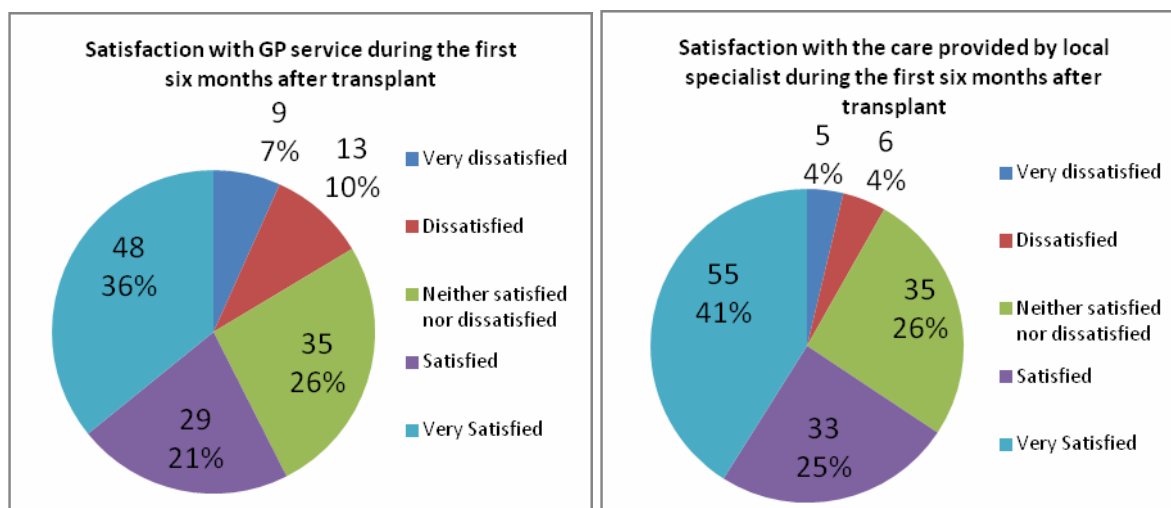
Care after transplant (Aftercare)

Questionnaire feedback

As part of the transplant recipient questionnaire, in addition to providing feedback on the quality of the transplant service, respondents were asked to provide comments on their experience of aftercare.

The charts below indicate the levels of satisfaction that questionnaire respondents expressed regarding the care provided by their GP, local specialist and transplant unit in the first six months post-transplant:

- 57% were satisfied or very satisfied with their GP service during the first six months after transplant.
- 66% were satisfied or very satisfied with the care provided by their local specialist during the first six months after transplant.
- 85% were satisfied or very satisfied with the care provided by the transplant unit during the first six months after transplant.



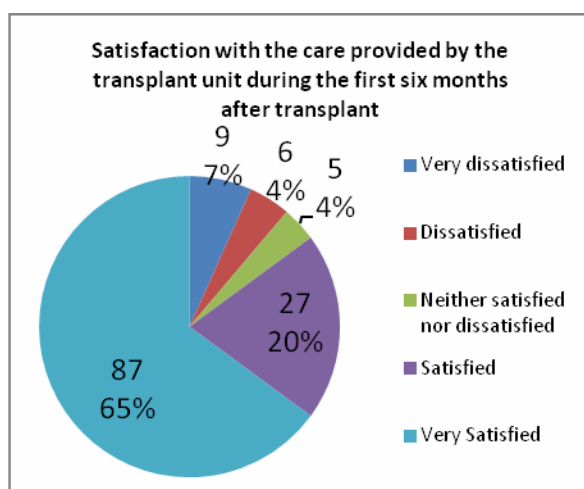


Figure 7 Transplant recipient satisfaction with the care provided by GP

Figure 8 Transplant recipient satisfaction with the care provided by local specialist

Figure 9 Transplant recipient satisfaction with the care provided by transplant unit

Positive areas

- In the first instance, most respondents are able to approach the transplant unit with any concerns about their health, and a number of people indicated that they get excellent care with the unit.

Variable areas

- The level of involvement and knowledge of GPs varied widely. Several people felt that they received good support from their GP, but fifteen respondents expressed feelings that their GP was unable to help, or lacking in knowledge about their transplant.

Negative areas

- A common difficulty in aftercare was having prescriptions filled for medications, with several people specifically mentioning trouble with pharmacies providing Valganciclovir.
- It was often felt to be unclear who people were meant to contact about a specific problem.
- There was frustration with a perceived lack of collaboration among medical professionals, such as the transplant unit not communicating necessary information to the GP.
- There were several concerns around medical error, such as receiving poor or wrong advice from healthcare professionals. In one case, a doctor forgot to check blood results, delaying a rejection diagnosis. Two other people mentioned difficulty with receiving medications when in hospital, as the nursing staff were not aware of a transplant recipient's particular needs.
- Several respondents felt that they were not listened to by the medical staff, with one saying, 'I'm a number not a person.'
- Certain annual reviews, such as skin care and skeletal surveys, were promised at the time of transplant but have never occurred locally.

Focus group feedback

Information available

- Several people mentioned good support available through being able to ask questions by email or phone.
- Difficulty knowing who to contact – NHS 24, transplant ward, GP, local hospital.
- Desire to access blood and other test results online (as renal transplant recipients are able to do through PatientView).

Psychological impact

- Psychological support available varied widely.
- Feelings of abandonment after discharge.
- The medications have an impact on emotions after transplant.
- Partner suffering emotionally after transplant.

The level of psychological support offered after transplant varied widely. Some participants received support at their local hospital or through social work; some had found support via social media; and some felt there was nothing available. One participant suggested that a patient 'orientation' group would be hugely beneficial in understanding what life would be like.

What is good healthcare after transplant?

- Preventative, anticipatory care.
- Care responsive to individual physical and emotional needs.
- Clear expectations about health in the short, medium and long-term.
- Timely, adequate and effective information sharing between transplant unit, local hospital and GP.
- Development of local support and local care co-ordination that starts on discharge.
- Local services empowered to undertake non-specialist tests.
- Interested and proactive GP and dispenser.
- Straightforward and timely access to the correct (branded) medications.
- Access (and fast track where necessary) to skin and skeletal checks, blood tests, physiotherapy, dietician, psychology.

Participants acknowledged that patients needed to take 'ownership' for their healthcare, not just blame the professionals, but emphasised that there needs to be better support for patients to know how to do this.

Many participants expressed difficulties dealing with their GP, with a number of concerns regarding the GP's knowledge and/or interest: 'I know my condition better than the GP'. A few participants, however, did indicate that their GP was able to offer some emotional, if not physical, support.

One concern was the way some participants felt abandoned due to lack of support after discharge. The comparison was made that, after a birth, a midwife would come by for check-ups; after liver transplant, there was no advice or check-up of pills or scarring. There were also concerns about follow-up tests, such as skin and skeletal checks, that never happened.

There were major concerns expressed regarding access to medications after transplant. A number of participants indicated that they keep a stockpile of drugs, as a result of delayed prescriptions and supply issues (pharmacy unable to obtain medication). There were also serious concerns about the correct brand of immunosuppressant being prescribed, rather than generics.

3.4. Management of medicines post-transplant

The Reference Group noted that the inadvertent switching of a number of branded immunosuppressants to generic medicines was a cause for concern. As critical-dose drugs with a narrow therapeutic index, medicines including Tacrolimus, Ciclosporin, and Sirolimus (patent expiring in 2015) have an associated risk of toxicity and graft rejection if patients are switched between brands without therapeutic monitoring and medical supervision.

A pharmaceutical subgroup was established and met once in July 2014. This subgroup involved a number of pharmacists and clinicians with expertise in immunosuppressive medicines and representatives from Healthcare Improvement Scotland, National Services Scotland, the Scottish Government and the Scottish Prescribing Advisors Association. The subgroup's aim was to consider the on-going management of the safety concern surrounding the risk of inadvertent switching of immunosuppressive medicines.

Current branded prescribing rates

In order to understand the scale of the issue, the subgroup undertook an assessment of prescribing rates by branded product for 2013/14. Results are displayed in Table 7 below. The percentage shown indicates the proportion of prescriptions where the brand was specified, rather than the generic name.

NHS Board	Ciclosporin	Tacrolimus	Sirolimus
NHS Ayrshire and Arran	84%	65%	0%
NHS Borders	88%	88%	0%
NHS Dumfries and Galloway	88%	79%	0%
NHS Fife	87%	80%	0%
NHS Forth Valley	82%	78%	19%
NHS Grampian	88%	91%	0%
NHS Greater Glasgow and Clyde	79%	69%	5%
NHS Highland	90%	88%	16%
NHS Lanarkshire	91%	89%	18%
NHS Lothian	91%	82%	3%
NHS Orkney	86%	81%	No Prescribing
NHS Shetland	75%	59%	No Prescribing
NHS Tayside	95%	88%	17%
NHS Western Isles	100%	87%	No Prescribing
NHS Scotland	86%	80%	7%

Table 7 Proportion of prescriptions issued by brand for Tacrolimus, Ciclosporin and Sirolimus during Apr 2013 - March 2014 [ISD prescribing data]

Figures in the fourth column relate to the number of prescriptions where Sirolimus was specified rather than Rapamycin. As Sirolimus is currently a patented product, patients will currently receive Sirolimus regardless of whether it or Rapamycin is specifically requested. Sirolimus comes off patent in 2015.

Consideration of patient feedback

Feedback from the patients on the patient focus groups has indicated that, as a transplant recipient, it is of crucial importance to become very good at managing and coordinating your own care. This includes ensuring that medicines prescribed and dispensed are the appropriate product as advised by the transplant programme, in instances where generic medicines have been advised by the prescriber or dispenser.

Another issue reported by patients is the availability of some infection prophylaxis and anti-viral medicines in pharmacists (e.g. Valganciclovir). As a result of supply issues, the majority of transplant recipients involved in focus groups have reported these medicines have to be ordered significantly in advance, and often stockpiled to ensure that a safe stock level is always available at home.

Group view on repatriation of prescribing

Both England and Wales have chosen to 'repatriate' patients receiving solid organ transplants from GP prescribing (with community pharmacy dispensing) to secondary care prescribing (with dispensing via secondary care arrangements including homecare or outsourced outpatient dispensing). There have been two drivers behind this change: patient safety (transplant specialists prescribing immunosuppressive agents and ensuring consistency of product supplied) and cost avoidance (dispensing through secondary care arrangements has enabled access to NHS contract prices).

At the meeting of the pharmaceutical subgroup, consideration was given to the secondary care prescribing approach that is being taken in England. Whilst the use of homecare does have the potential to ensure consistent branded prescribing – as all prescriptions are being routed through a small number of pharmacies – the group concluded that given the risks and other consequences of this approach, it would be disproportionate to adopt a repatriation policy in Scotland on safety/quality grounds. Service problems in the homecare market have highlighted the fragility of this supply route and have led to the issue of a patient safety alert on the risk of missed or delayed doses.⁵³ Homecare can also fragment care, create inconvenience for patients, disempower patients, and remove patient choice. As such, it was recommended that Scotland should not adopt a repatriation policy on safety/quality grounds.

⁵³ NHS England (2014). Patient safety alert on minimising risks of omitted and delayed medicines for patients receiving homecare services. Available online: <http://www.england.nhs.uk/2014/04/10/psa-min-risks/>

4. Activity

The incidences outlined throughout this section have been derived from the Office of National Statistics⁵⁴ and General Registers Office of Scotland.⁵⁵

4.1. Historical activity

4.1.1. Waiting lists

Transplant waiting list	At 31 Mar 2011	At 31 Mar 2012	At 31 Mar 2013	At 31 Mar 2014	At 30 Sept 2014
Kidney	518	482	515	473	438
Kidney/pancreas	29	16	24	19	23
Pancreas (+islets)	4	6	13	12	17
Heart	13	14	8	18	15
Lung(s)	14	19	16	18	21
Heart/lung	1	1	1	1	1
Liver	46	59	48	54	44
Other (multi-organ)	2	0	0	0	0
Total	627	597	625	595	559

Table 8 Number of patients on transplant waiting lists [NHSBT]. Excludes patients temporarily suspended from the transplant list.

Table 9 shows an overall reduction in the size of the transplant waiting lists between 31 March 2011 and 30 September 2014.⁵⁶ Despite an additional 82 transplants being undertaken in 2013/14 than in 2010/11, the total size of the transplant waiting lists reduced by 32 over the same period. This indicates that with increasing transplantation activity, whilst the overall sizes of the waiting lists are reducing, the reduction is not proportional to the increase in activity. This will be as a result of more patients being placed on the waiting list for transplantation, which will reflect referral rates to the service and an increased need for transplantation. The increased referrals will also reflect that more patients are now being referred to be reassessed for second transplants.

	Change in numbers on transplant lists (31 Mar 11 - 31 Mar 14)	Change in annual transplant activity (2010/11- 2013/14)
Kidney	-45	+58
Kidney/pancreas	-10	+4
Pancreas (+islets)	+8	0
Heart	+5	+10
Lung(s)	+4	+11
Heart/lung	0	0
Liver	+8	-1
Other (multi-organ)	-2	-

⁵⁴ Office of National Statistics population estimates and projections. Available from: <http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk-england-and-wales-scotland-and-northern-ireland/population-estimates-timeseries-1971-to-current-year/rft-table-1-total-persons-constituent-countries-regions.zip>; <http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2012-based-extra-variants/rft-table-z7-zipped-population-data-files-uk.zip> [Accessed 23 April 2014].

⁵⁵ General Registers Office of Scotland mid-year population estimates. Available from: <http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/mid-year/archive/2007/index.html>; <http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/mid-year/archive/2008/index.html>; <http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/mid-year/archive/2009/index.html>; <http://www.gro-scotland.gov.uk/files2/stats/population-projections/2010-based/proj-pop-scot-2010.pdf>; <http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/mid-year/2012/index.html> [Accessed 23 April 2014].

⁵⁶ The NHSBT Annual Centre Specific Report 2013/14 for kidney transplant shows that while the waiting list in Edinburgh has decreased, the one in Glasgow has increased. With the implementation of national commissioning of adult renal transplant, these types of differences will be evaluated by NSD.

Total	-32	+82
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Table 9 Change in numbers on transplant lists (31 March 2011 – 31 March 2014) and annual transplant activity (2010/11 – 2013/14) [NHSBT and services]

4.1.2. Solid organ transplantation activity

Figure 10 shows the 149% growth in transplantation activity in Scotland (and on Scottish residents at Freeman Hospital) over 19 years from 167 transplants (32.7 pmp) in 1995/96 to 416 transplants (78.1 pmp) in 2013/14.

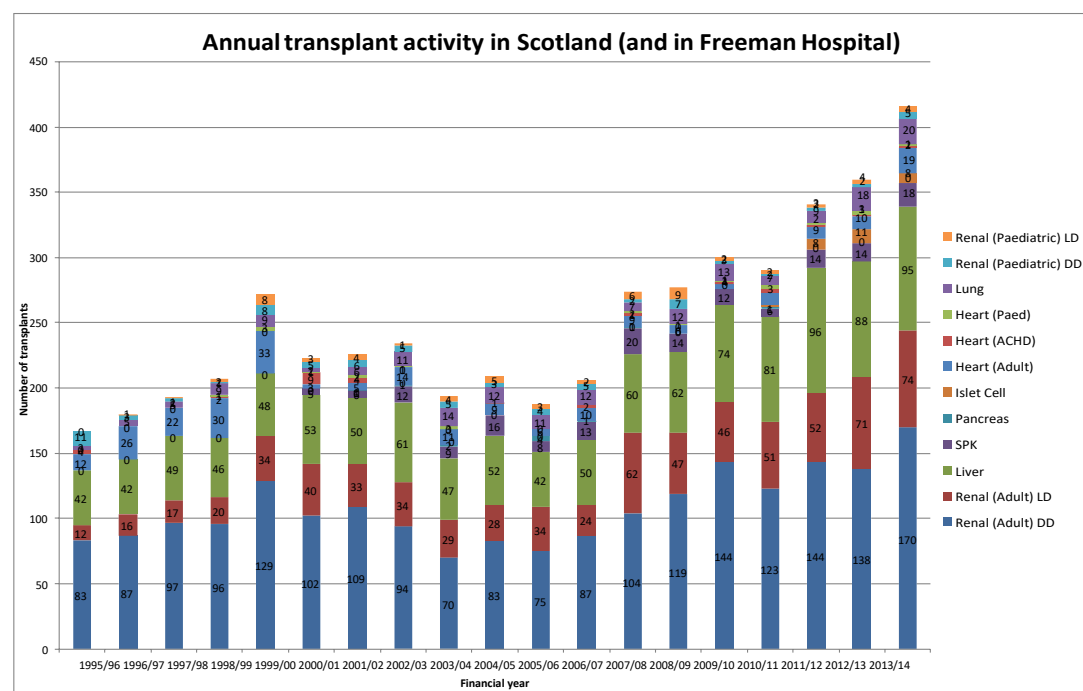


Figure 10 Annual transplant activity in Scotland and in Freeman Hospital

4.1.3. Cardiothoracic transplantation activity

Figure 11 shows the annual levels and trends for cardiothoracic transplantation on Scottish residents. There was growth in adult heart transplant activity to 1999/2000, followed by a dip in activity and a slow resurgence of growth. Lung transplantation activity has also increased.

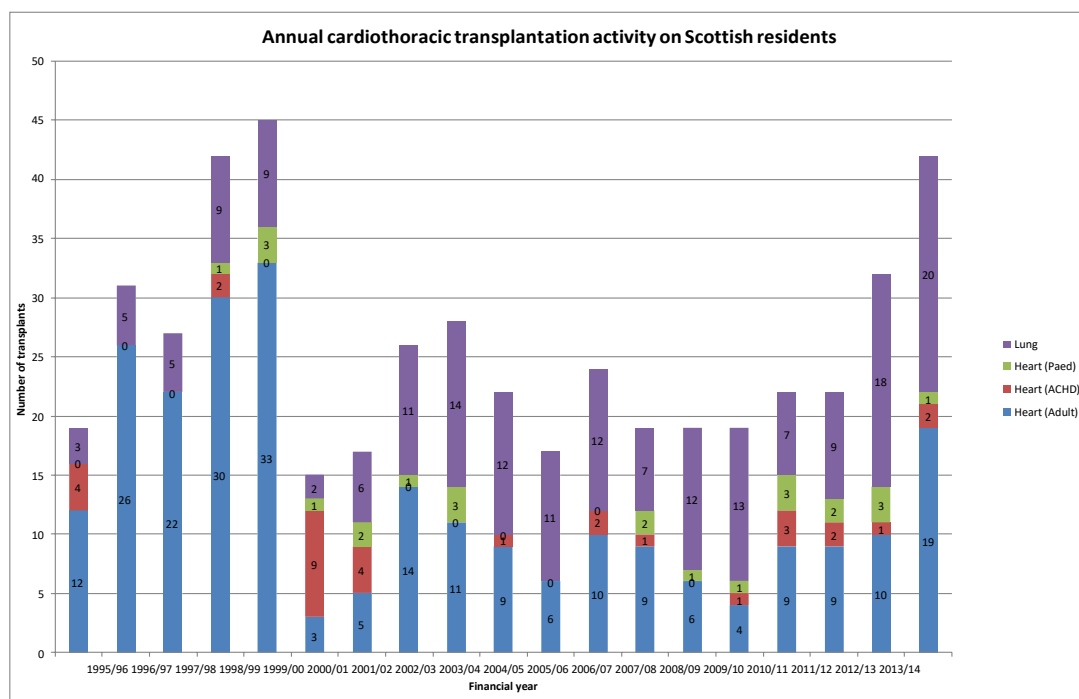


Figure 11 Annual cardiothoracic transplantation activity on Scottish residents

4.1.4. Abdominal transplantation activity

Figure 12 shows the annual levels and trends for abdominal transplantation on Scottish residents. There has been notable growth in deceased donation and living adult renal, liver and simultaneous pancreas kidney transplantation activity over the period. There was slow growth in abdominal transplant activity to 2006/07, after which the rate of activity has increased more swiftly.

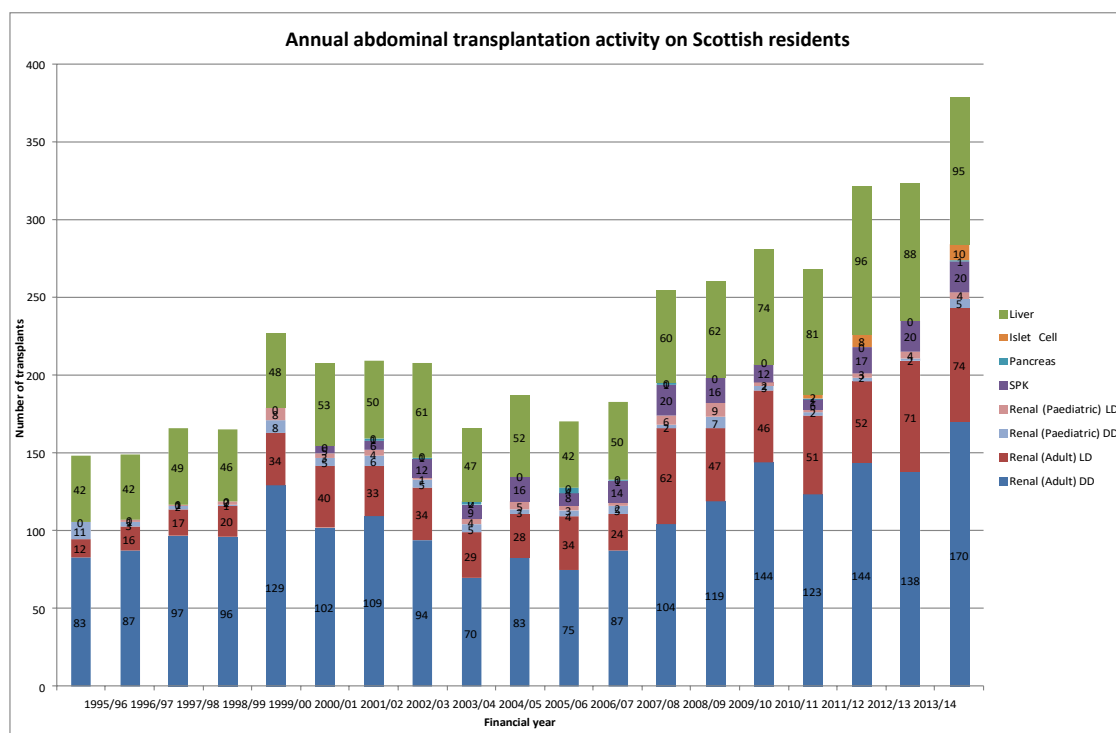


Figure 12 Annual abdominal transplantation activity on Scottish residents

4.2. Future activity

4.2.1. Organ donation

Historical activity

Year	Number of deceased donors						Incidence (pmp)					
	UK			Scotland			UK			Scotland		
	DBD	DCD	Total	DBD	DCD	Total	DBD	DCD	Total	DBD	DCD	Total
2007-08	609	200	809	41	13	54	10.0	3.3	13.3	8.0	2.5	10.5
2008-09	611	288	899	51	21	72	10.0	4.7	14.6	9.9	4.1	13.9
2009-10	624	335	959	47	16	63	10.1	5.4	15.5	9.0	3.1	12.1
2010-11	637	373	1010	49	18	67	10.2	6.0	16.2	9.4	3.4	12.8
2011-12	652	436	1088	53	28	81	10.3	6.9	17.2	10.1	5.3	15.4
2012-13	705	507	1212	56	38	94	11.1	8.0	19.0	10.5	7.2	17.7
2013-14	780	540	1320	62	44	106	12.2	8.4	20.6	11.6	8.2	19.9

Table 10 UK and Scottish deceased donor organ donation activity and incidence pmp 2007/08 - 2013/14 [NHSBT]

Organ donation activity is the driver of transplantation activity, and so in forecasting the potential growth in organ transplantation, organ donation forecasting was required in the first instance. As seen in the table above, the increase in Scottish donation incidence over the past 7 years reflects a degree of 'catch up' with the rest of the UK. The NHS Blood and Transplant Regional Manager who covers the Scotland region presented forecasts to the Reference Group and provided reassurance that 26pmp deceased donors by 2020 would be achievable. A breakdown of this forecast is presented in the table below.

Activity	Additional DBD donors	Additional DCD donors	Total additional deceased donors
DBD referral (society / hospital development / education)	2	0	2
DCD referral (society / hospital development / education / screening / belief)	0	11	11
DBD testing (stabilisation of potential donors / ethics)	4	0	4
DBD/DCD non approaches (hospital development)	1	2	3
DBD authorisation (society / SNOD involvement / designated requirements)	8	0	8
DCD authorisation (society / timings / SNOD involvement / designated requirements)	0	8	8
Population increase (forecast to be 5.48m in 2020)	0	1	1
Total	15	22	37

Table 11 Additional activity required to increase deceased donation incidence to 26pmp

Figure 13 outlines historical activity between 2007/08 and 2013/14 and provides forecasts to 2020 by deceased donor organ type.

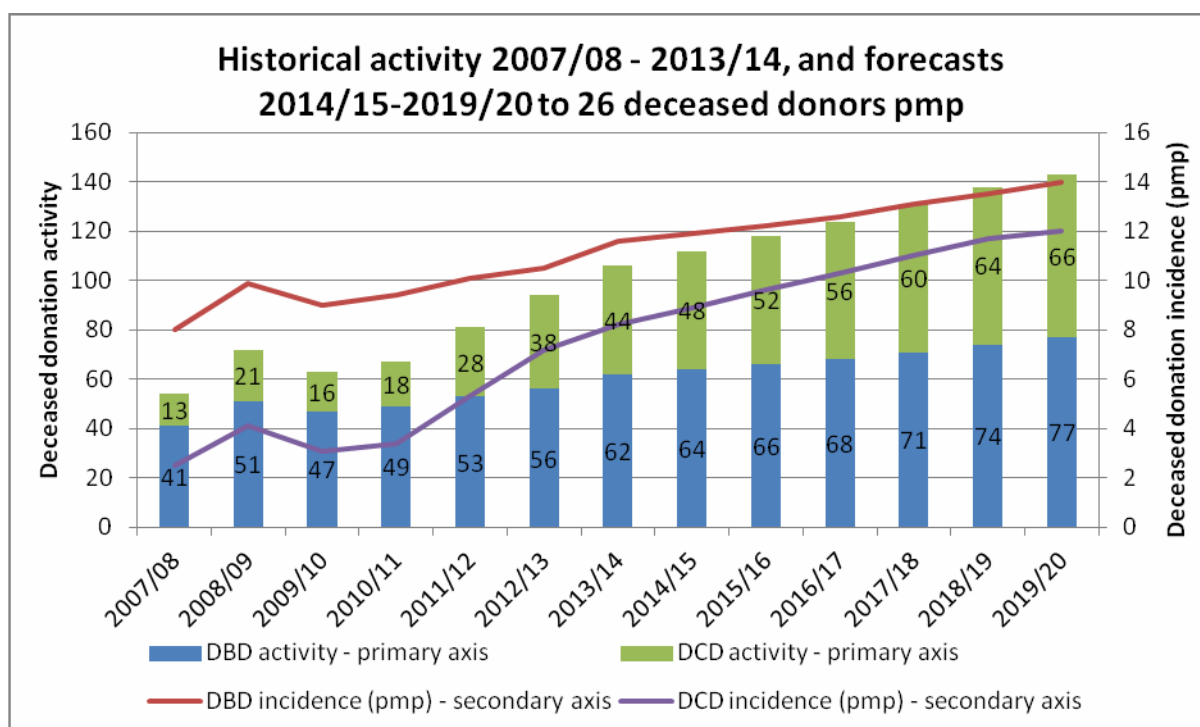


Figure 13 Deceased donation. Historical activity (2007/08–2013/14) and forecasts (2014/15–2019/20) to 26 deceased donors per million population [NHSBT]

The NHSBT Regional Manager has outlined the aspiration to increase the incidence of deceased donation further to 30pmp. This could occur with sustained improvements in relationships, logistics, and team working among the SNODs, referring units, and organ retrieval teams across NHS Scotland; the development of donor referral education; the further development of insightful authorisation requesting; and cultural changes. Figure 14 outlines the forecast growth in deceased donation in this more optimistic model.

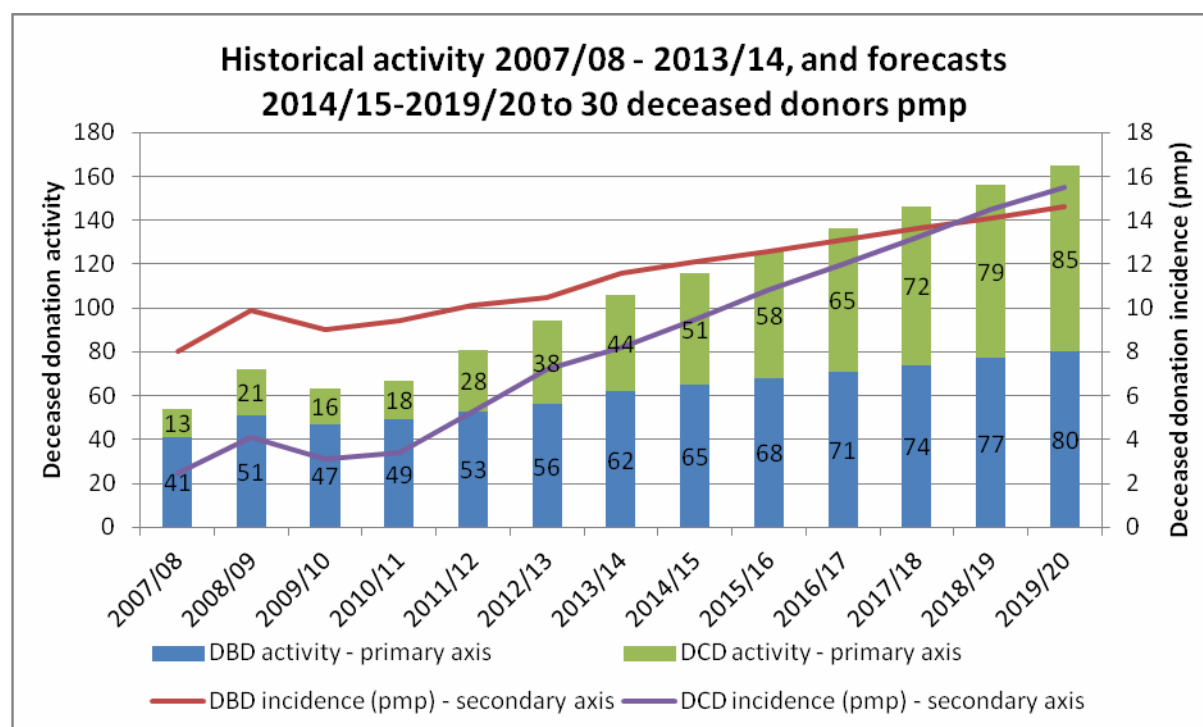


Figure 14 Deceased donation. Historical activity (2007/08–2013/14) and forecasts (2014/15–2019/20) to 30 deceased donors per million population [NHSBT]

This more optimistic forecast sees increases predominantly in DCD donation activity. As Novel Technologies in Organ Transplantation are currently still being evaluated, the potential associated increase in donation activity has not been considered within these two models. In reality, it is likely that the deceased donation rate will be somewhere in the region of 26-30pmp in 2020.

4.2.2. Organ transplantation

Assumptions

The projections depend on many factors including:

- Changes in clinical practice (e.g. perfusion techniques)
- Sufficient resources to achieve the activity increases (within NHS Scotland and NHSBT)
- No major loss of public confidence in organ donation or transplantation
- No major changes in health care delivery

Projections

When developing transplantation forecasts to 2020, the Reference Group considered the predicted growth in deceased and living organ donation activity, trends in the incidence of underlying disease, activity trends to date, and the size of waiting lists.

As it is acknowledged that the further the forecasts are made into the future, the less reliable they become, the Commissioning Board agreed that the Reference Group should focus on planning for the growth over the next three financial years (2015/16, 2016/17, and 2017/18), with annual review by NSD during the implementation phase.

Commissioning Transplantation to 2020

Transplant type	Deceased Donor (DD) / Living Donor (LD)	Annual number of transplants						
		2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20
Adult Renal	DD ⁵⁷	172	176	190	208	221	234	241
	LD ⁵⁸	81	81	96	107	116	123	123
Adult Liver	DD	95	110	110	120	120	131	131
	LD ⁵⁹	2	2	2	2	2	2	2
Adult Heart	DD ⁶⁰	19	16	16	17	18	18	18
Adult ACHD Heart	DD	2	2	3	3	4	4	5
Adult Lung	DD ⁶¹	20	20	21	23	24	25	26
Adult Kidney/Pancreas	DD ⁶²	18	15	15	15	15	15	15
Adult Kidney/Pancreas (N. Irish cohort)	DD ⁶³	3	5	5	5	5	5	5
Adult Pancreas-alone	DD	0	1	0	0	0	0	0
Adult Pancreas-alone (N. Irish cohort)	DD	1	0	0	0	0	0	0
Adult Islet	DD ⁶⁴	11	14	16	17	20	24	30
Adult Islet (N. Irish cohort)	DD ⁶⁵	2	3	3	3	4	4	5
Adult Small Intestinal	DD	2	2	2	2	2	2	2
Adult Heart/Lung	DD	0	0	0	0	0	0	0
Paediatric Renal ⁶⁶	DD	5	4	4-6	4-6	4-6	4-6	4-6
	LD	4	6	4-6	4-6	4-6	4-6	4-6
Paediatric Heart	DD	1	1	1	³⁶⁷	³⁶⁷	³⁶⁷	³⁶⁷
Total Transplants		438	458	494	535	571	600	616
Increase from 2013/14		-	5.0%	12.8%	22.1%	30.4%	37.0%	40.6%

Table 12 Actual transplantation activity 2013/14, and forecasts 2014/15-2019/20

Table 12 above contains the Reference Group's projected transplantation forecasts for the population of Scotland from 2014-2020, in the context of the actual transplantation activity for 2013/14. Table 13 presents these figures as incidences per million population.

The NHS Blood and Transplant strategy and Scottish Government plan aim to increase deceased donor transplantation to 74pmp. The Scottish incidence of transplantation is higher than the UK incidence due to the greater underlying incidence of contributing disease in Scotland. As a result, when the Reference Group considered the forecasts to 2020, these take the deceased donor transplantation incidence to 88.4pmp which exceeds the 74pmp. The services have considered this in light of the UK incidences for deceased donor transplantation and have agreed that this level of forecast activity is nonetheless appropriate and feasible.

⁵⁷ Service forecasts to 2017/18 – growth of 11% per year (above UK incidence). Forecast from 2018/19-2019/20 based upon further 3% increase per annum.

⁵⁸ Service forecasts to 2017/18 – above UK incidence. After 2017/18, the activity level remains static.

⁵⁹ In line with UK incidence

⁶⁰ Service agree with forecast activity levels based on UK incidence

⁶¹ Based upon UK incidence

⁶² Scottish activity based on 85.7% of the total SPK activity forecast. Service forecast total growth for Scottish and Northern Irish patient cohort of 2 SKP per year (and fewer pancreas alone), from 20 SKP + 1 pancreas only in 13/14 to 32 SKP in 2019/20

⁶³ Northern Irish activity based on 14.3% of the total SPK activity forecast. Growth forecasts as per above.

⁶⁴ Scottish activity based on 84.6% of the total islet transplant activity (as per 2013/14)

⁶⁵ Northern Irish activity based on 15.4% of the total islet transplant activity (as per 2013/14)

⁶⁶ Overall, it is likely that there will be an increase in pre-emptive transplantation and in the need for ABO and HLA incompatible transplants. Paediatric renal activity forecast likely to be highly variable due to low annual numbers.

⁶⁷ Estimate of 3 to represent a range of 2-4 transplants per year.

Commissioning Transplantation to 2020

Transplant type	Deceased Donor (DD) / Living Donor (LD)	Annual transplant incidence (pmp) ⁶⁸						
		2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20
Adult Renal	DD ⁶⁹	32.2	32.8	35.3	38.4	40.6	42.8	43.9
Adult Liver	DD ⁷⁰	17.8	20.5	20.4	22.2	22.1	24.0	23.9
Adult Heart	DD	3.6	3.0	3.0	3.1	3.3	3.3	3.3
Adult ACHD Heart	DD	0.4	0.4	0.6	0.6	0.7	0.7	0.9
Adult Lung	DD ⁷¹	3.7	3.7	3.9	4.2	4.4	4.6	4.7
Adult Kidney/Pancreas	DD ⁷²	3.4	2.8	2.8	2.8	2.8	2.7	2.7
Adult Pancreas-alone	DD ⁷³	0.0	0.2	0.0	0.0	0.0	0.0	0.0
Adult Islet	DD	2.1	2.6	3.0	3.1	3.7	4.4	5.5
Adult Small Intestinal	DD	0.4	0.4	0.4	0.4	0.4	0.4	0.4
Adult Heart/Lung	DD	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Paediatric Renal	DD	0.9	0.9	0.7	0.7	0.7	0.7	0.7
Paediatric Heart	DD	0.2	0.2	0.2	0.6	0.6	0.5	0.5
Total deceased donor transplant incidence (pmp)		65.7	69.0	71.6	77.6	80.9	85.9	88.4
Increase in incidence from 2013/14		-	4.9%	9.0%	18.0%	23.1%	30.6%	34.5%
Adult Renal	LD ⁷⁴	15.2	15.1	17.8	19.8	22.6	22.5	22.4
Adult Liver	LD	0.4	0.4	0.4	0.4	0.4	0.4	0.4
Paediatric Renal	LD	0.7	1.3	1.1	1.1	1.1	1.1	1.1
Total living donor transplant incidence (pmp)		16.3	16.8	19.3	21.2	24.1	24	23.9
Increase in incidence from 2013/14		-	3.0%	18.4%	30.4%	47.9%	47.2%	46.6%

Table 13 Actual transplantation incidence 2013/14, and forecasts 2014/15-2019/20

⁶⁸ Incidences derived from General Registers of Scotland projections

⁶⁹ Adult renal DD: Incidence in 2019/20 of 46.5pmp against 42.9pmp forecast originally using NHS BT data

⁷⁰ Adult liver DD: Incidence in 2019/20 of 23.9pmp against 17.0pmp forecast originally using NHS BT data

⁷¹ Adult lung: Incidence in 2019/20 of 4.7pmp against 4.6pmp forecast using originally NHS BT data

⁷² Adult Simultaneous Kidney Pancreas: Incidence in 2019/20 of 4.9pmp against 4.7pmp forecast originally using NHS BT data

⁷³ Adult pancreas alone: Incidence in 2019/20 of 0.0pmp against 1.0pmp forecast originally using NHS BT data

⁷⁴ Adult renal LD: Incidence in 2019/20 of 22.4pmp against 19.6pmp forecast originally using NHS BT data

4.3. Transplanted organs in patients in Scotland

The figure and table below outline the number of transplanted organs in patients in Scotland as of 31 March 2014. These indicate that transplant recipients live in every NHS Board area across Scotland, from 10 transplant recipients in NHS Orkney to 1,343 in NHS Greater Glasgow and Clyde.

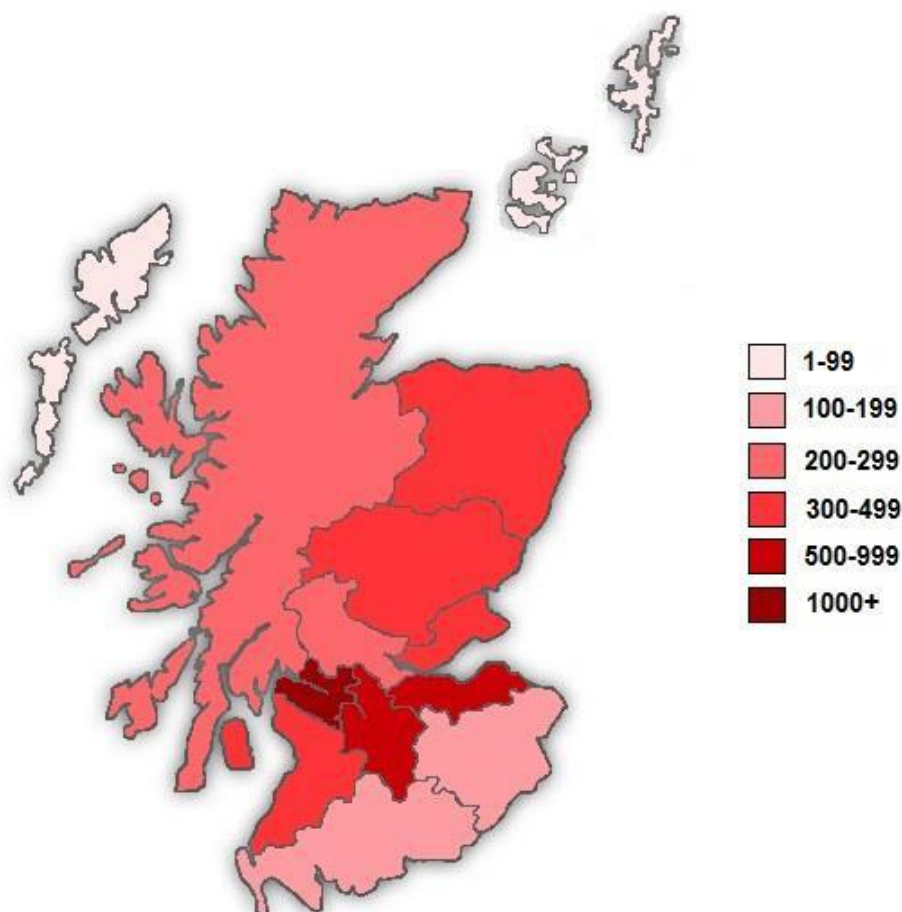


Figure 15 Number of transplanted organs in transplant recipients in Scotland by NHS Board as of 31 March 2014

Total number of surviving transplanted organs in transplant recipients in Scotland, as of 31 March 2014															
Organ transplant type	NHS Board of residence of transplant recipients' residence														Total
	A&A	BOR	D&G	FIF	FV	GRA	GGC	HIG	LNK	LOT	ORK	SHE	TAY	WI	
Heart & kidney	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Lung & liver	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Intestinal failure	-	-	-	-	-	-	-	-	-	-	-	-	-	-	9
Heart/lung	-	-	-	-	-	-	-	-	-	-	-	-	-	-	11
Pancreas	-	-	-	-	-	-	-	-	-	-	-	-	-	-	12
Liver & kidney	-	-	-	-	-	-	-	-	-	-	-	-	-	-	16
Pancreas islets	-	-	-	7	-	-	8	-	-	-	-	-	-	-	28
Lung	-	-	-	6	8	13	33	-	12	22	-	-	8	-	113
Kidney/pancreas	12	-	-	14	6	19	27	12	20	17	-	-	17	-	153
Heart	20	6	9	14	14	14	45	12	28	30	-	-	21	-	215
Liver	52	25	35	72	48	74	247	53	91	193	8	-	47	11	958
Kidney	223	81	98	209	182	364	974	203	406	517	9	8	262	12	3548
Total	314	119	154	326	262	492	1343	290	559	793	19	10	358	26	5065

Table 14 Total number of transplanted organs in transplant recipients in Scotland by NHS Board as of 31 March 2014. (In accordance with disclosure control purposes for small area statistics, data for NHS Boards with 5 organs transplanted or below have been suppressed.)

It is clear that with a growing incidence of transplantation and improving survival, the prevalence of transplant recipients in Scotland will also increase rapidly. This will increase follow-up activity post-transplant. These patients will also have additional requirements for medications and support from the specialist transplant services, local units and community care. There will be a growing financial impact on NHS Scotland, due to improved survival times and the cost of follow-up care and immunosuppressant medications, though this will be partially offset by savings in the reduction of care for long-term conditions, such as dialysis. The increasing number of transplant recipients will impact on primary care, as more GPs have transplant recipients in their practice, and on secondary care, as transplant recipients require use of local hospital services. There is also a growing cohort of live kidney donors in Scotland, who require follow-up care. The increasing numbers of these patients will have significant resource impact on NHS Scotland. However, good after-care is key to ensuring successful patient outcomes, and hence the provision of optimal after-care for all transplant recipients and living donors is essential.

5. Developments

5.1. Histocompatibility and Immunogenetics

Histocompatibility and Immunogenetics (H&I) supports the organ transplantation services through Human Leukocyte Antigen (HLA) typing, which assesses the closeness of the match between the tissues of the transplant recipient and those of the potential donor. The H&I laboratory also performs HLA antibody screening and crossmatching. Timely and accurate H&I support is required to help maximise the function of the transplanted graft.

The projected increase in the deceased organ donation rate from 17.9pmp to 26.0pmp (and the projected increase in the transplantation rate from 65.8pmp to 88.4pmp) will impact on the two H&I services. With increasing transplant activity and complexity, it has been recognised that there will be an increase in the associated H&I workload. Work has been undertaken between the two providers of the H&I service in Scotland (SNBTS and NHS Greater Glasgow and Clyde) and the review team to ensure that the service is able to meet the needs of patients in the future.

Increase in deceased donor and living donor HLA typing

Deceased and living donor HLA typing performed during normal working hours will utilise staff time that would be spent on supporting 'routine' H&I solid organ transplantation activity, and haematopoietic stem cell transplantation, blood transfusion and disease association diagnostic services. The impact of this will be an increase in turnaround times for all tests.

Increased numbers of deceased donor HLA types performed out of hours will result in increased compensatory rest periods, which will reduce the capacity of the service to meet demand. It is worth noting that in approximately 40-50% of DCD cases, donor typing is undertaken where there is ultimately no subsequent transplant.

Increase in deceased donor and living donor prospective crossmatches

Increased crossmatch activity will negatively impact on the turnaround time of other tests performed by the laboratory due to staff time spent performing prospective (and retrospective) crossmatches, including compensatory rest time for out-of-hours activity.

Increase in ABOi and HLAi transplant activity

It is likely that some of the increase in transplantation activity will be achieved by performing ABO and HLA incompatible transplants. The latter requires an increase in the number of tests pre-transplant, specifically HLA alloantibody monitoring, by the H&I laboratory (further information below).

Post transplant monitoring will become routine

Monitoring patients for de novo post transplant alloantibodies will become routine and will aid "personalised immunosuppression" strategies. This activity will increase as transplant activity increases.

5.1.1. Change in technologies

HLA alloantibodies

There are no significant changes predicted regarding the technology used, and the specificity and sensitivity of the current technology for HLA alloantibody analysis will improve. It is also predicted that there will be an increase in the complexity of analysis of patient's alloantibodies, such as distinction between complement fixing and non-complement fixing antibodies and distinction between antibody reactivity against native and non-native HLA proteins. This increase in complexity will increase the time required to accurately define a sensitised patient's alloantibody status, as more tests will be necessary to achieve this.

The benefit of determining the HLA alloantibody status to a higher degree of complexity will be a concomitant increase in prospective virtual crossmatching for deceased donor transplants.

Non-HLA alloantibodies

There are a number of non-HLA alloantibodies that have been identified as impacting on transplant outcome. To date there are no robust data supporting their impact and no routine methods to allow their identification; however this could change within the next 6 years, and the H&I laboratories would have to accommodate this additional testing.

HLA typing

Quicker solutions for deceased donor typing are likely to arise. The Edinburgh laboratory currently has an automatic typing system (FluoVista) which has been shown to reduce the time taken to generate an HLA type for deceased donor testing by 50 minutes. The benefit of quicker donor HLA typing will be to speed up the allocation process and to save staff time.

IT solutions

Remote access to H&I databases is beneficial for out-of-hours assessment of individual patient's sensitisation history and is a necessity to agree a prospective virtual crossmatch. At present, Glasgow have this facility (albeit cumbersome) and Edinburgh do not.

5.2. Therapeutic apheresis for renal transplantation

Removal of antibodies is indicated to support certain types of renal transplantation:

- a. Electively, to desensitise patients prior to planned living transplantation where there is ABOi and/or HLAi incompatibility between the recipient and donor, and
- b. In the emergency setting, to treat patients with acute antibody mediated rejection (AMR) following renal transplantation. This can occur in the immediate post transplant period or as a late event, months or years after the transplant episode.

Currently, all antibody removal in this context is carried out by plasma exchange (PEX) provided by Scottish National Blood Transfusion Service (SNBTS) using centrifugal technology. Modified haemofiltration technology can also be used for plasma exchange, but because of the complexity of the needs of the patient who is experiencing acute AMR or who requires elective desensitisation, plasma exchange is provided by SNBTS out of its Edinburgh or Glasgow Clinical Apheresis Units (CAUs) using centrifugal technology. There

has been no desire voiced during the ongoing pan-Scotland therapeutic apheresis service review to change this service delivery model.

Many centres elsewhere in the UK and in Europe, the United States and Australasia have moved from plasma exchange to column technology as the preferred technology for antibody removal in these cases. This is because there are distinct clinical benefits to the patient of column technology over plasma exchange. In addition, column technology offers a more efficient method of antibody removal and so it is possible to achieve the same level of antibody removal after one column procedure that is achieved after 4 or 5 plasma exchanges. However, the consumable costs associated with column technology are far higher than those associated with plasma exchange.

Other factors impacting on plasma exchange support requirements include case selection, and, consistent with gaining experience, it is anticipated that the number of ABOi and HLAi cases undergoing live transplantation will rise over time. The BTS/BSHI guidelines suggest a minimum of 5 per year of each should be performed. With the implementation of national commissioning of adult renal transplantation, the levels of activity will be monitored by NSD in order to ensure the maintenance of expertise.

The pan-Scotland review of Clinical Apheresis is currently being considered by the Directors of Planning, and recommendations on the future provision of the service are expected shortly.

5.3. Novel Technologies in Organ Transplantation

The demand for transplantation has increased significantly in recent years. In Scotland, we have seen a substantial increase in the number of donors to bridge the gap between demand and supply. Like in many other parts of the country, the increase has been primarily in donation after circulatory death.

The review of current preservation and perfusion technologies identified that cold static perfusion has been the backbone of organ perfusion and preservation for the last 30 years. Whilst this is satisfactory for the current practice, the demographic changes of the donor population and the expansion in the utilisation of extended criteria donors may require alternative approaches in order to increase organ utilisation and the quality of organs recovered for transplantation.

The UK transplant community is therefore exploring novel approaches to improve the overall outcome for the transplanted organ, such as:

- Normothermic regional perfusion, in the donor at the time of organ retrieval
- Machine perfusion, which may include the period of transport of the organ
 - Hypothermic machine preservation
 - Hypothermic machine preservation with oxygen delivery
 - Normothermic machine preservation
- Ex-vivo perfusion
 - Ex-vivo normothermic perfusion
 - Ex-vivo hypothermic perfusion

There are currently several trials exploring the use of Novel Technologies in Organ Transplantation, which are being coordinated by a national NHSBT Novel Technologies in

Organ Transplantation working party, which is assessing applicability for these organs, and implementation.

The potential novel technologies assessed by each group are listed in the table below.

	Liver	Kidney	Pancreas	Heart	Lung
Donor	Normothermic regional perfusion (NRP)	Normothermic regional perfusion (NRP)	Normothermic regional perfusion (NRP)		
Preservation	Ex-vivo normothermic machine preservation (NMP)	Hypothermic machine preservation (HMP)	Hypothermic machine preservation (HMP)	Ex-vivo normothermic preservation (NMP)	
	Hypothermic machine preservation (HMP)	Hypothermic oxygenated machine preservation (HMP-OX)			
Ex-vivo / re-conditioning	Ex-vivo normothermic perfusion (EVNP) (Organ Assist)	Ex-vivo normothermic perfusion (EVNP)	Ex-vivo normothermic perfusion (EVNP)		Ex-vivo lung perfusion (EVNP) (EVLP)
	Hypothermic oxygenated perfusion (EVHP)(HOPE)		Pancreas Persufflation (PP)		

Table 15 Potential novel technologies in organ transplantation, by type and organ

Several models for implementation are envisaged, depending on the impact on organ recovery and organ quality, the expertise available and the scale of investment. Several potential technologies that could be combined along the transplantation pathway have been identified. These should be considered for further evaluation and a step-wise implementation.

Several technologies appear to have a beneficial effect on the organ recovery rates, organ quality, and transplant rates. Based on the current predicted costs, there will be a significant variation in the gain/benefit ratio for each technology. This may be offset in the long term by an increased organ recovery, modulation of organ donor quality, and ultimately higher transplantation rates.

Some technologies will have an impact at NORS teams level (NRP and all preservation technologies), whilst some will require changes at the transplant centre level (all perfusion technologies).

Based on the current available evidence, at present no technology can be recommended for a national scale implementation.

5.4. Research opportunities

In February 2014, the National Institute for Health Research (NIHR) announced an open competition to award research funding of £15 million over five years to universities in England to drive forward priority blood and transplantation research in the following four priority areas in partnership with NHSBT:

- (Blood) Donor health, behaviour and population genomics

- Organ donation and transplantation
- Haematopoietic stem cell transplantation and immune therapies
- Generation of blood cells in vitro

As the National Institute for Health Research (NIHR) provides a core service to England, Scottish universities were not invited to attract funds from the organisation.

Research drives innovation in working practices, supports improvements in the quality of clinical services, supports service sustainability and growth, gives rise to more effective and cheaper treatments, and generates income.

All of the transplant units in Scotland have good partnerships with the Universities. However, it is essential that opportunities are sought where possible to ensure that the Scottish transplantation services are able to continue to innovate in line with the transplantation services across the rest of the UK.

5.5. Potential designation of new national services

NHS Lothian has expressed an interest in:

- The national designation of the existing fulminant hepatic failure service, as an extension to the current liver transplantation service. NHS Lothian is currently the sole Scottish provider of this service, which is provided on a non-nationally commissioned basis for residents of Scotland.
- The creation of a new paediatric liver transplantation service after the re-provision and associated co-location of the Royal Hospital for Sick Children with the Royal Infirmary of Edinburgh. This service is currently provided for Scottish children in Birmingham, King's College, and Leeds.

NHS National Waiting Times Centre Board has expressed an interest in:

- The provision of a Scottish lung transplantation service.
- ACHD transplantation services in the future.

Both of these cardiothoracic transplantation services are currently provided in Freeman Hospital, Newcastle for residents of Scotland.

6. Finance

6.1. Context

The projected increase in organ availability and associated transplantation activity will have a significant impact on the costs associated with transplantation services. As NSD only funds the specialist services, this financial profile does not include transplant aftercare.

In light of the financial situation within the public sector, there can be no new developments for any of the specialist services including transplantation. NSD will liaise with each transplantation service and review activity on an annual basis, bearing in mind the activity forecasts set by the Reference Group. Increased transplantation activity will have to be at least partially funded by increased efficiencies across the national services, including the transplantation services.

6.2. Expenditure by service

As outlined in Table 12, transplantation activity is projected to continue to grow by a further 34.5% between 2014/15 and 2020, from 458 to 616 transplants per annum. The figures below outline the associated increase in costs based upon the increases attributed to a 1% inflationary uplift per annum, and increases in variable costs associated with increased activity. As adult renal transplantation will not be commissioned nationally by NSD until 2015/16, expenditure is only included from 2014/15 (to provide a baseline) to 2019/20.

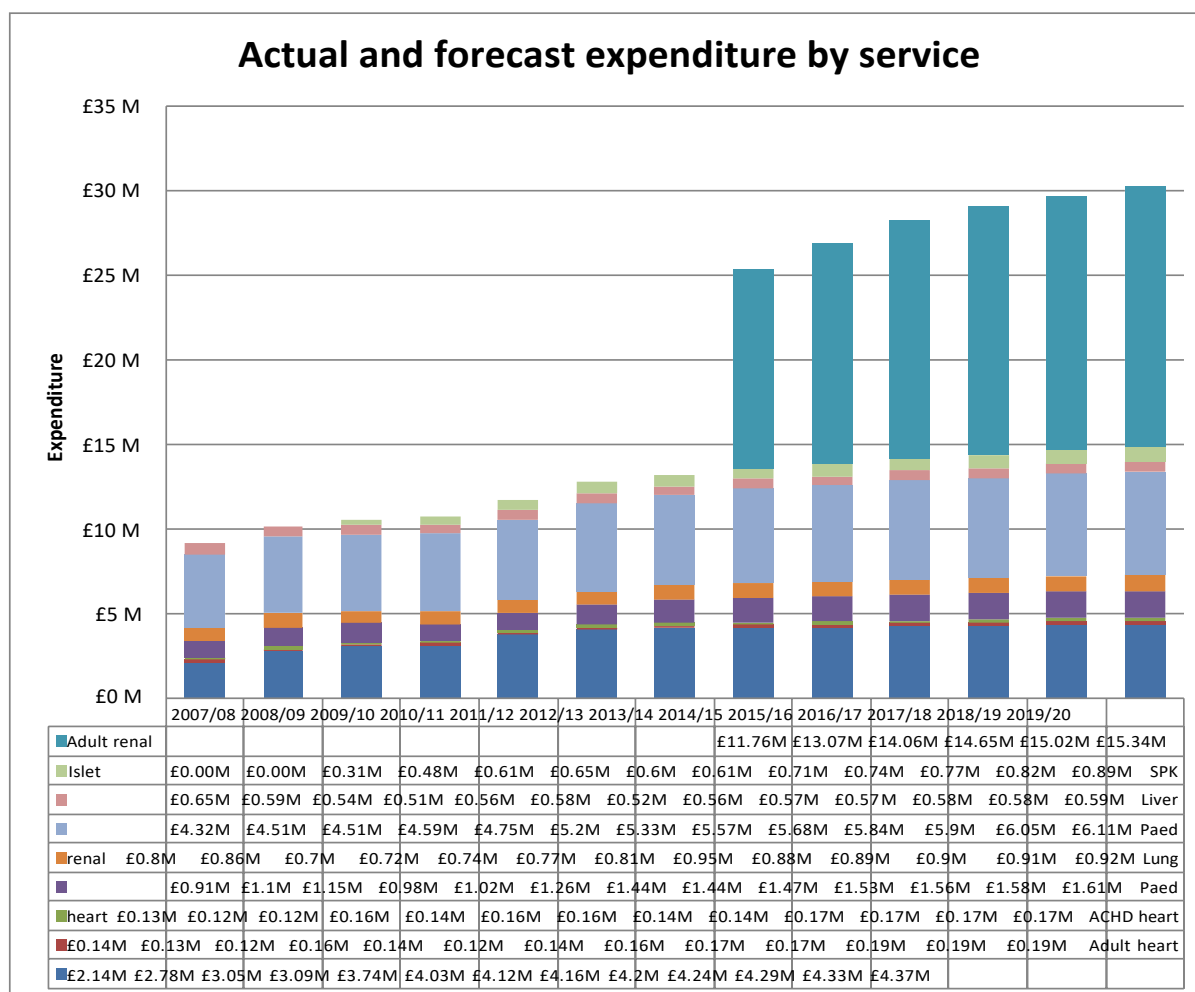


Figure 16 Actual and forecast expenditure by service

Figure 16 shows an increase in the total expenditure on solid-organ transplantation services from £9.11m on 108 transplants in 2007/08 to £13.12m on 173 transplants in 2013/14. Future expenditure is forecast to increase by £4.85m from £25.34m in 2014/15 to £30.19m in 2019/20. This is predominantly as a result of the additional £3.58m of investment required to support increased adult renal transplantation activity. When excluding adult renal transplantation activity, costs for the remaining transplantation services increase by £1.26m over the same period.

6.3. Cost per case

Figure 17 highlights that total cost per case peaked in 2009/10 (a year associated with low cardiothoracic and islet activity), but then fell as a result of increased activity by 2013/14. Cost per case is projected to reduce further over the next six years in line with increased activity and services working to maximise the use of their funded capacity. Cost per case for the cardiothoracic programmes varies significantly due to effect of low and variable activity levels on cost per case.

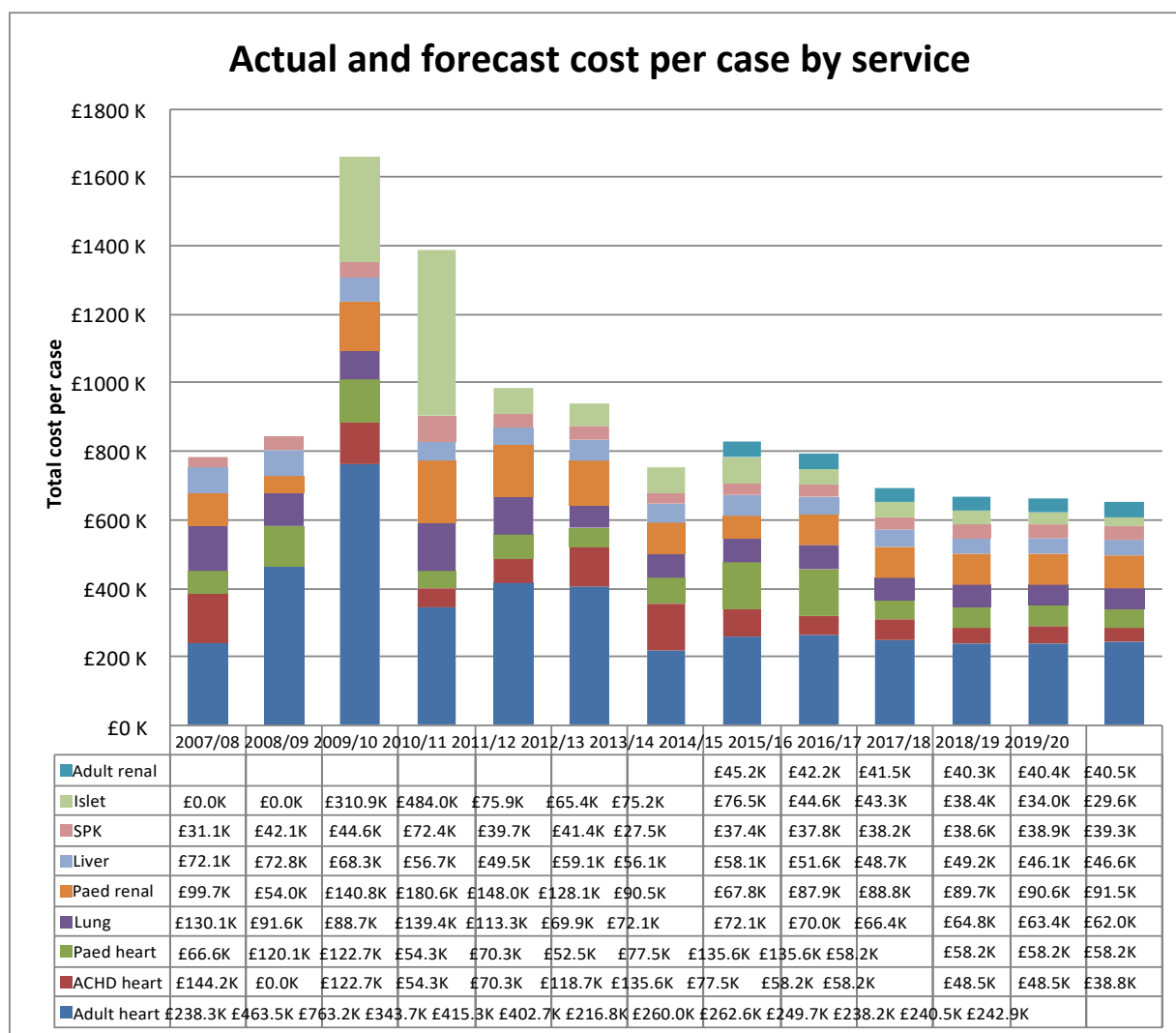


Figure 17 Actual and forecast cost per case by service

7. Health and social care resource impact analysis

7.1. Background

Organ transplantation is an expensive and complex procedure, involving not just the surgical team but many different NHS resources. It does, however, have the potential to be transformative in the lives of patients and families.

This section examines transplantation from an economic, rather than financial, perspective, by applying financial valuations to the increases in the quantity and quality of life achieved (as measured by Quality Adjusted Life Years (QALYs)). It shows that the benefits accrued from the projected transplant activity in Scotland to 2020 outweigh the costs.

Increasing transplant activity in line with the forecast figures would result in an additional 1000 QALYs over that of 2013/14, with a financial valuation of approximately £60 million for an additional spend of around £5.4 million. This is before including the value of possible savings, including the cost of alternative treatment.

7.1.1. Other relevant studies

The UK-wide strategy 'Taking organ transplantation to 2020' examined the results from a previous analysis done by the (then) NHS West Midlands, which had concluded that:

"There is a clear financial benefit for renal transplantation, as this is a real alternative to dialysis and results in a significant cost saving. This is not the case for other organs, for which the cost of transplantation outweighs the cost of end-of-life care."

*However, given that it would not be ethical or practical to promote specific types of organ donation, it is accepted that renal transplantation cross-subsidises all other types of organ transplantation."*⁷⁵

The authors of the UK strategy considered that this conclusion remains relevant, subject to costs being kept under review. The NHS West Midlands report was primarily a financial, rather than economic, assessment, though it did note that:

*"The analysis does not set out to review in any great detail the cost effectiveness of organ transplantation and the qualitative benefits that are evidenced in published medical and similar journals, which can demonstrate clearly in favour of organ transplantation in most, if not all organs."*⁷⁶

The West Midlands work was quite extensive and involved building a model to assess the costs of solid organ transplants in the UK, the comparator costs of non-transplant treatment options, and the costs or savings that might be realised by increasing organ donation by 50%. It also included an evidence review on the costs and cost effectiveness of solid organ transplantation.⁷⁷

⁷⁵ NHS Blood and Transplant (2013). Taking Organ Transplantation to 2020. Economic case for organ transplantation. <http://www.nhsbt.nhs.uk/to2020/the-strategy/supporting-documents/economic-case-for-organ-transplantation.pdf> [Accessed 29 January 2015].

⁷⁶ West Midlands Specialised Commissioning Team (2010). Organs for transplant: An analysis of the current costs of the NHS transplant programme; the cost of alternative medical treatments, and the impact of increasing organ donation.

⁷⁷ Longworth, L., et al. (2010). Organs for Transplants – Review of the evidence on the cost and cost-effectiveness of solid organ transplantation (heart, liver, lung and pancreas). Health Economics Research Group: Brunel University. Report to the West Midlands Specialist Commissioning Team.

The review showed that renal transplant has the most extensive and robust evidence base in terms of both costs and cost effectiveness. This is supported by a 2010 systematic literature review on economic evaluation of transplantation.⁷⁸ This is unsurprising given that renal failure not only has the longest history of transplantation but also a comparator treatment of dialysis. For many other conditions in which a solid organ transplant is the treatment of choice, there are few, if any, treatments that would give the anticipated extension in life comparable to a transplant.

An impact assessment was also carried out to inform the Human Transplantation (Wales) Bill. The provision in the Bill was to move to a system of deemed consent for organ donation, which would exist alongside expressed consent. Supporting evidence on the costs and benefits of the provision in the Bill is provided in the regulatory impact assessment.⁷⁹ This involved a comparison of cost and benefits of transplant (for kidney, heart, liver and lung) over 10 years. The approach was to value costs and benefits on a discrete, rather than on continuous, basis. For example, one additional kidney transplant patient in year 0 (the year of the first additional transplant) was estimated to cost £152,000 over 13 years of expected survival. One additional kidney transplant patient in year 1 would generate the same costs and so on for one additional transplant in each of years 2-9. Costs were then discounted over the 10 year appraisal period. The same approach was used to estimate QALY benefits and savings against dialysis.

7.1.2. Methodology

The interest of this report is in the costs and benefits generated in the period up to 2020, a relatively short period of time. We have assumed that the costs to NHS Scotland are as provided by NSD. In general the costs are roughly of the same level of magnitude as those estimated by the Department of Health (DH) and used in the Welsh assessment. Though we do not have the cost of alternative care, by using NSD data and by uprating the DH data, similar analyses to Wales have been replicated for specific transplant types.

We can also estimate a monetary valuation of the benefit generated by both total numbers and the increased number of transplants planned. We cannot estimate the cost effectiveness of the procedures, nor should this be considered as a full cost benefit analysis due to the difficulty in quantifying many of the benefits described both here and in the social and public health impact analysis.

7.2. Impact

7.2.1. Costs

Increasing the number of organs donated and transplanted within Scotland will result in costs to a number of different individuals and groups.

Donors

Increasing number of donors means an increased number of families affected. The transplant programme relies on individuals and their relatives agreeing to organ donation. In most cases, this will be from those recently deceased, although living donation is possible

⁷⁸ Jarl, J., & Gerdtham, U-G. (2012). Economic evaluations of organ transplantations: a systematic literature review. *Nordic Journal of Health Economics*. 1(1), 61-82.

⁷⁹ Welsh Government (2012). Human transplantation (Wales) Bill: Explanatory memorandum incorporating the Regulatory Impact Assessment and Explanatory Notes.

for some transplants. This means that there could be stress and anxiety associated with this decision for an increased number of families. This is impossible to quantify: for some relatives, organ donation may lessen the stress; for others, it may increase it. For living donors, there are risks associated with any surgery which may represent a cost, even if only very short term (e.g. health status and/or the ability to work).

Recipients

Although transplantation is clearly of benefit to recipients, it is not without cost. The whole experience imposes costs in terms of anxiety and stress. Post-transplant, there may be side effects from medication and anxieties about rejection and/or infection. These may result in a reduction, however temporary, in wellbeing.

An increased number of transplants will mean more families of recipients experiencing the stress associated with waiting for transplant (including the assessment process), the operation itself, and any uncertainty associated with the outcome. This could mean additional costs for support, including psychological support, for patients and relatives.

NHS Scotland

Increasing the number of transplants will increase the costs of the service. Transplantation activity is constrained not only by the supply of organs, but also by the resources available within NHS Scotland. Increasing the number of transplants will impose additional costs.

One area which may impose additional costs is the use of novel technologies to increase the number of potential donor organs, mainly after circulatory death. These are discussed in section 5 of the report and there is currently a national working party investigating the applicability of these. It is difficult to estimate the final cost, although it is likely that substantial capital expenditure will be required to establish these.

Any additional transplant activity has the potential to have an impact on other hospital services, not just the staff directly involved. This will include pharmacy, laboratory services, physiotherapy, and counselling services. These costs are not reflected here. Section 8 of the report summarises the likely impact on the capacity of services to deliver the projected increase in transplant activity.

In addition, resources devoted to an increasing number of transplant patients may result in the displacement of activity from other areas to transplant patients. Increased transplantation activity will have to be, at least in part, resourced through increased efficiency across all services, including transplantation.

Follow-up services will be affected by an increased number of patients. The impact will be dependent on the model of care adopted: secondary care led (as outpatients); shared care between GPs and secondary care; or GP led. If follow-up is to be mainly within primary care, there may be costs involved in ensuring that GPs and other primary care providers are sufficiently informed about care for these patients. From the recipient survey, it seems that that there may also be unmet demand for support services after transplant.

Direct costs have been estimated from cost information submitted to NSD. These are detailed by year in section 6.2 and recapped in Table 16. The base year is 2013/14. (The

costs are of the same magnitude as those estimated for the Welsh impact assessment and the West Midlands report.)

Transplant type	Unit cost of transplant 2013/14 (£)	Total costs 2013-2020 (£Ms)	Total cost 2013-20 discounted (£M)
Adult			
Kidney (DD)	41,454	56.2	50.5
Kidney (LD)	55,532	35.7	32.1
Liver	56,117	40.5	36.5
Heart	216,818	29.7	26.8
Heart (ACHD)	135,618	1.2	1.1
Lung	72,092	10.6	9.6
Pancreas	27,513	4	3.6
Islet ⁸⁰	75,157	5.1	4.6
Paediatric			
Renal	90,474	6.2	5.6
Heart	77,534	1.1	1.0
Total		£190.3m	£171.4m

Table 16 Estimated transplant costs

Assumptions:

- No assumption is made around rising unit costs – it is assumed that these remain stable, in real terms, over the period up to 2020.
- Costs are discounted at 3.5 % as per treasury guidance.
- The costs of providing the service to Northern Irish patients are omitted, but it should be noted that there is scope for income generation, as NHS Scotland currently carries out adult pancreas and islet cell transplant for patients from Northern Ireland.
- The table excludes costs for small bowel transplantation.

Potential for cost saving

The West Midlands report stated that, at time of publication, the UK transplant programme realised annual gross savings of £316 million per annum to the NHS, compared to the cost of alternative medical treatment. Increasing organ transplant rates by 50% could achieve a further cost saving of £200 million per annum to NHS commissioners. The savings came primarily from renal transplantation. This conclusion was supported by the NHSBT strategy.

As stated, renal transplant is proven to be cost effective, as successful transplantation negates the need for dialysis. NSD estimates the annual cost of dialysis to be approximately £33,000. By 2020, it is forecast that a total of 364 annual kidney transplants would be carried out, with 111 of these being an increase to the activity in 2013/14. The dialysis cost for these would be approximately £12.5 and £5.6 million respectively. An increase in transplants would result in the potential for fewer patients to require dialysis. Patients who receive pancreatic or islet cell transplant would otherwise have been receiving insulin therapy. In 2013/14, NHS Scotland spent £75.7m on drugs to treat diabetes in the community.⁸¹ £30.6m was spent on insulin.

⁸⁰ Islet cell transplantation costs include a cost for lab services.

⁸¹ ISD Scotland (2014). Prescription cost analysis. Available from: <http://www.isdscotland.org/Health-Topics/Prescribing-and-Medicines/Community-Dispensing/Prescription-Cost-Analysis/> [Accessed 29 January 2015].

The vast majority of patients have their long term follow up care in primary care, from their GP, which means that the prescribing of immunosuppressants is, for the most part, a local responsibility. NSS Procurement Commissioning and Facilities is in discussions with Scottish Government on options to access savings within existing care pathways.

There will be savings to the wider public sector if more people are in employment and fewer people are receiving benefits because they are too ill to work. Research evidence suggests that, although return to work rates vary, there is certainly considerable scope for recipients to return to the workforce.

7.2.2. Benefits

An increased number of transplants will result in benefits to a number of individuals and sectors of society. Many of these are difficult to quantify.

Donors

An increase in living donors will result in an increase in welfare overall, including to these individuals and their families, as are they are able to contribute to the health and wellbeing of a relative or, in the case of altruistic donors, to a stranger.

For deceased donors, more families may find comfort and value the health gain to a number of other individuals as a result of the death of a family member.

Recipients

As well as the increase in both quantity and quality of life that would be gained from increased transplant activity, benefits may include reduced waiting times. This would reduce the stress and anxiety that accompanies being on the waiting list. Increased quality of life could be through increased ability to participate in work and leisure activities, as well as regaining independence after a period of illness.

An increased number of families will also experience the increase in welfare as their relative receives a transplant. This may be through, for example, a reduction in stress and anxiety whilst awaiting a transplant and a reduction in caring responsibilities after transplant.

More people are receiving transplants and surviving longer after transplant. In March 2014, there were over 5000 transplanted organs in transplant recipients in Scotland. Amongst the benefits reported by respondents to the recipients' questionnaire were improved family life, emotional wellbeing, ability to return to work and/or play sport, and (for kidney patients) freedom from dialysis. As numbers increase, there is more that can be learned on how best to monitor, support, and, if necessary, treat recipients.

NHS Scotland

As the scale and scope of transplant activity continues to expand, there will be an increase in knowledge and expertise within the transplant community in Scotland. This in turn could facilitate a continued increase in the quality and quantity of work able to be carried out by NHS Scotland to the benefit of patients. The use of novel technologies is an example where this is likely to increase the number of kidneys recovered with good results.

Any additional work for services, either directly or indirectly through increased scale and scope of transplant activity (e.g. laboratory services, pharmaceutical services, allied health

professional services such as physiotherapy, psychology), will lead to increased expertise, which should benefit future patients. This applies equally to follow-up services for recipients.

Society

Wider society will benefit from having fewer people chronically ill, with the health and social care resource use that is involved. It will also benefit from these individuals being more likely to be productive economic actors. There may also be an increase in general well-being as organ donation is increasingly seen as the cultural norm.

7.3. Quality Adjusted Life Year (QALY)

In much of the economic evaluation literature, in particular that on cost effectiveness, the most common metric in terms of estimating and valuing benefit is the Quality Adjusted Life Year (QALY). This uses the scale 0 – 1 to measure both quality and quantity of life; a score of 1 is equivalent to 1 year in full health.

Many of the QALY values quoted here have been sourced from the Brunel work, which cautions that evidence on cost effectiveness, including QALY estimates, on all types of transplantation was very limited at the time of writing. In addition, a great deal of the data was old and not necessarily applicable to the NHS. Clinical practices and associated costs may have changed in the interim. However, their review is used here, along with other sources, to produce an estimate of the benefit from increasing the numbers of transplants.

Kidney and pancreas

Kidney transplants are by far the most common: as seen in Table 14, they make up 70% of transplanted organs in transplant recipients in Scotland. When assessing the potential impact for changing to deemed consent for organ donation, the Welsh Government assumed QALY gains for transplanted patients, based on calculations done for the DH (2006). These estimates were that, when compared with dialysis, the patient would gain 4 QALYs over 13 years of life.⁸² The Brunel review found the QALY gain to be between 1.4 and 1.8 QALYs over 5 years, with slightly higher values for a living donor than a deceased donor.

There were higher QALY values (2.36) for a Simultaneous Pancreas-Kidney (SPK) transplant. These values are consistent with the DH estimates used by Wales. Values from the DH estimated a QALY gain which varied from 2 to 4.6.⁸³ The Brunel study concluded that there was limited quality data on the costs of pancreas-alone transplant and was therefore unable to determine QALY.

Considering these estimates, we have assumed that kidney transplant will result in 2, 6 or 5 additional QALYs per patient, for deceased donor, living donor, and SPK transplants respectively.

Liver

Scotland has a large burden of liver disease, mainly, though not exclusively, from alcohol related disease. The Welsh Impact Assessment assumed that, over 18 years, a liver transplant patient enjoyed the equivalent of an additional 13 QALYs over a patient who is

⁸² Welsh Government (2012). Human transplantation (Wales) Bill: Explanatory memorandum incorporating the Regulatory Impact Assessment and Explanatory Notes.

⁸³ Organ Donation Taskforce – Supplement Report 2008 DH England. Available from: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_082121.pdf [Accessed 29 January 2015].

medically managed. A cost effectiveness analysis of liver transplantation calculated a range of estimates, depending on the type of liver disease treated. The study covered only 27 months (chosen to represent 3 months on the waiting list and 2 years post-transplant) and calculated a QALY gain of 0.5 over this short time period.⁸⁴ The DH 2008 work estimated a QALY gain from liver transplants of 11.5 per patient. The Welsh estimate is used here.

Heart

The Brunel review found that cost effectiveness studies on heart transplant are rare. One European study found a gain of 6.8 QALYs for heart transplant.⁸⁵ The Welsh assumption was that patients who had undergone a heart transplant would gain 7 QALYs over 10 years and is used here.

Lung

As of 31 March 2014, there were 113 lung transplants in recipients living in Scotland. The Brunel study identified seven cost effectiveness studies on lung transplants using QALY values as outcome measures. The most applicable to the NHS was a UK study that estimated a QALY gain of 3.0, 4.1, and 4.4 (for single lung, double lung, and heart-lung transplants respectively).⁸⁶ The Welsh assumption for lung transplantation was that patients had a median survival time of 5.5 years (compared to 2 years on medical management) and that they gained 4 QALYs. This is the estimate used here.

Islet cell

A US model of islet transplantation estimated that islet transplantation was cost effective over insulin therapy and offered cost savings after 9-10 years, with an additional QALY gain of 1.6 QALYs over 10 years.⁸⁷ In our estimates, we have rounded this to 2 QALYs.

Small bowel

It was not possible to find a quantitative assessment of the costs and benefits of small bowel transplantation in literature.

Paediatric transplants

Studies of paediatric renal transplantation show a survival advantage for patients who receive transplants, in comparison with those who undergo dialysis.⁸⁸ The lifespan of a child on dialysis is estimated to be 40-60 years less, and that of a paediatric transplant recipient 20-25 years less, than that of age and race-matched general populations. We have therefore assumed a gain in life years in comparison with dialysis of 30 years and a QALY value of 0.9 per year giving a QALY gain of 27.

A recent US review of paediatric heart transplantation gave estimates of survival in the modern era for patients transplanted at different ages: 19.7 years, 16.8 years, 14.5 years,

⁸⁴ Longworth, L., et al. (2003). Midterm cost effectiveness of the liver transplantation program of England and Wales for three disease groups. *Liver Transplantation*. 9(12), 1295-307.

⁸⁵ Ouwens, J.P., et al. (2003). The cost effectiveness of lung transplantation compared with that of heart and liver transplantation in the Netherlands. *Transplant International*. 16(2), 123-7.

⁸⁶ Anyanwu, A.C., et al. (2002). An economics evaluation of lung transplantation. *Journal of Thoracic and Cardiovascular Surgery*. 123(3), 411-8.

⁸⁷ Beckwith, J., et al. (2012). A health economic analysis of clinical islet transplantation. *Clinical Transplantation*. 26(1), 23-33. Reviewed in *NHS Economic Evaluation Database (NHS EED)*.

⁸⁸ Saeed, B. (2012). Pediatric Renal Transplantation. *International Journal of Organ Transplantation Medicine*. 3(2), 62-73.

and 12.4 years (for infants, 1-5 yr olds, 6-10 yr olds, and 11-17 yr olds, respectively).⁸⁹ As a working assumption, we have assumed that these years are at less than full health (0.8 of a QALY), and we have assumed an average total gain of 13 QALYs.

QALY gain

Organ Transplanted	Kidney		SPK	Liver	Heart	Lung	Islet	Paediatric	
	DD	LD						Heart	Kidney
QALY gain	2	6	5	13	7	4	2	27	13

Table 17 Assumption re QALY gains used in benefit estimates

It is assumed that each patient who undergoes a transplant has a gain in Quality Adjusted Life Year (QALY) as detailed in Table 17, dependent on the type of transplant undergone.

7.4. Valuation of QALYs

There is a division amongst health economists about whether or not QALYs should be given a monetary value. Government departments tend to favour the approach where valuation of the QALY can be derived from the same empirical base used to value a prevented fatality. This makes it broadly consistent with the value of life or (more accurately) the value of a prevented fatality (VPF) used by the UK Department for Transport (DfT) in the appraisal of transport safety. This is essentially a “willingness to pay” (WTP) figure.⁹⁰ The current valuation used by DH is £60,000 per QALY.

Table 18 shows the results of applying this valuation to the assumptions made about the QALY benefits attributed to each type of transplant. The base year is taken as 2013/14, and the QALY values are discounted at 1.5% per annum.⁹¹ Note that the financial valuations have been rounded to the nearest million £.

Transplant type	Total QALY gain 2013- 20	Total QALYs discounted	Total QALY value 2013 – 20 (£M)	total QALY gain (Discounted) (£M)
Adult				
Kidney (DD)	2898	2763	174	166
Kidney (LD)	4195	3994	252	240
Liver (DD)	10682	182	637	608
Liver (LD)	26	174	11	10
Heart	854	817	51	49
Heart (ACHD)	161	153	10	9
Lung	636	607	39	36
SPK	494	473	30	28
Islet cell	211	200	13	12
Paediatric				
Kidney (DD)	945	905	57	54
Kidney (LD)	1080	1031	65	62
Heart	190	180	11	11
Total	22,467	21,428	£1,348 M	£1,286 M

Table 18 QALY benefits and value (£M) from transplants (NHS Scotland) 2013/14 – 2019/20

The Scottish projections assume that there would be no increase in the number of small intestine transplants, no heart-lung transplants, and one potential pancreas-alone transplant over the period to 2020.

⁸⁹ Thrush, P.T., & Hoffman, T.M. (2014). Pediatric heart transplantation—indications and outcomes in the current era. *Journal Thoracic Disease*. 6(8), 1080-96. doi: 10.3978/j.issn.2072-1439.2014.06.16.

⁹⁰ This is a standard valuation technique also referred to as contingent valuation.

⁹¹ Current guidance from DH is to discount health benefits at 1.5% per annum (= estimate of pure time preference).

These estimates suggest that increasing the number and types of transplants in line with the forecasts would result in **total benefits** of over **21,000 QALYs** (discounted). This is an **increase** of around **1000 QALYs** over the level in 2013/14 with a discounted value of benefits of just under **£60 million**.

7.5. Estimated costs and benefits

With the exception of renal transplantation, it is difficult to estimate the cost of alternative treatment which would be avoided by transplant, as for many patients there may be no, or very limited, alternative treatment. Methodology based on the Welsh impact assessment is used to give an indication of the level of economic impact of transplantation of major organs. Scottish data on the costs of dialysis is available and utilised in these estimates. Elsewhere, data from DH is used as an indication of the likely cost of medical management. Where necessary, the DH figures are inflated to 2013/14 values using the Treasury GDP deflators.⁹² Financial valuation of a QALY remains at £60,000 with discount rates for costs of 3.5% and benefits of 1.5%. Survival time for patients is also taken from the Welsh study unless otherwise stated.

Kidney (Deceased Donor)

Increase in QALYs from transplant	2
Median survival time for transplanted patients	13 yrs
Median survival time on medical management	11 yrs
Cost of transplant surgery (2013/14) ⁹³	£41,454
Valganciclovir	£7,150
Annual cost of immunosuppressants	£5,060
Follow-up year 1	£700
Follow-up subsequent years	£150
Annual cost of kidney dialysis	£32,953

Table 19 Renal transplants: deceased donor assumptions

year	costs	QALY benefits	savings	net benefit
0 (2013/14)	112,000	120,000	362,000	371,000
1	112,000	120,000	362,000	371,000
2	112,000	120,000	362,000	371,000
3	112,000	120,000	362,000	371,000
4	112,000	120,000	362,000	371,000
5	112,000	120,000	362,000	371,000
6	112,000	120,000	362,000	371,000
7 (2019/20)	112,000	120,000	362,000	371,000
NPV	£708,000	£2,294,000	£209,000	£2,390,000

Table 20 Annual costs and benefits for one additional renal transplant (DD) per year

Kidney (Living Donor)

Increase in QALYs from transplant	6
Median survival time for transplanted patients	13 yrs
Median survival time on medical management	11 yrs
Cost of transplant surgery (2013/14) ⁹⁴	£55,532
Valganciclovir	£7,150
Annual cost of immunosuppressants	£5,060
Follow-up year 1	£700
Follow-up subsequent years	£150

⁹² <https://www.gov.uk/government/collections/gdp-deflators-at-market-prices-and-money-gdp>

⁹³ NSD – average cost calculated from Edinburgh and Glasgow data.

⁹⁴ NSD – average cost calculated from Edinburgh and Glasgow data

Commissioning Transplantation to 2020

Annual cost of kidney dialysis	£32,953
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Table 21 Renal transplants: living donor assumptions

Commissioning Transplantation to 2020

year	costs	QALY benefits	savings	net benefit
0 (2013/14)	126,000	360,000	362,000	597,000
1	126,000	360,000	362,000	597,000
2	126,000	360,000	362,000	597,000
3	126,000	360,000	362,000	597,000
4	126,000	360,000	362,000	597,000
5	126,000	360,000	362,000	597,000
6	126,000	360,000	362,000	597,000
7 (2019/20)	126,000	360,000	362,000	597,000
NPV	£797,000	£241,100	£2,294,000	£3,908,000

Table 22 Annual costs and benefits for 1 additional renal transplant (LD) per year

Liver

Increase in QALYs from transplant	13
Median survival time for transplanted patients	18 yrs
Median survival time on medical management	1.5 yrs
Cost of transplant surgery (2013/14) ⁹⁵	£56,117
Assessment ⁹⁷	£9,639
Candidacy ⁹⁷	£7,497
Follow up years 1 & 2 ⁹⁷	£12,853
Follow subsequent years ⁹⁷	£5,355
Annual cost of medical management ⁹⁷	£23,563

Table 23 Liver transplant assumptions

year	costs	QALY benefits	savings	net benefit
0 (2013/14)	185,000	780,000	35,000	631,000
1	185,000	780,000	35,000	631,000
2	185,000	780,000	35,000	631,000
3	185,000	780,000	35,000	631,000
4	185,000	780,000	35,000	631,000
5	185,000	780,000	35,000	631,000
6	185,000	780,000	35,000	631,000
7 (2019/20)	185,000	780,000	35,000	631,000
NPV	£1,169,000	£5,224,000	£136,000	£4,279,000

Table 24 Annual costs and benefits for 1 additional liver transplant per year

Heart

Increase in QALYs from transplant	7
Median survival time for transplanted patients ⁹⁶	10 yrs
Median survival time on medical management	4 yrs
Cost of transplant surgery (2013/14) ⁹⁵	£216,818
Annual cost of follow-up ⁹⁷	£12,853
Annual cost of medical management ⁹⁷	£5,355

Table 25 Cardiac transplant assumptions

⁹⁵ NSD

⁹⁶ Welsh Impact Assessment

⁹⁷ Welsh impact assessment updated

year	costs	QALY benefits	savings	net benefit
0 (2013/14)	345,000	420,000	21,421	96,000
1	345,000	420,000	21,421	96,000
2	345,000	420,000	21,421	96,000
3	345,000	420,000	21,421	96,000
4	345,000	420,000	21,421	96,000
5	345,000	420,000	21,421	96,000
6	345,000	420,000	21,421	96,000
7 (2019/20)	345,000	420,000	21,421	96,000
NPV	2,186,000	£2,813,000	£136,000	£736,000

Table 26 Annual costs and benefits for 1 additional cardiac transplant per year

Lung

Increase in QALYs from transplant	4
Median survival time for transplanted patients	5.5 yrs
Median survival time on medical management	2 yrs
Cost of transplant surgery (2013/14) ⁹⁵	£72,092
Follow-up year 1	£89,969
Follow-up year 2	£23,563
Follow-up year 3	£9,639
Follow-up year 4	£8,568
Follow-up year 5	£4,284
Annual cost of medical management year 1 ⁹⁷	£19,279
Annual cost of medical management year 2 ⁹⁷	£16,066

Table 27 Lung transplant assumptions

year	costs	QALY benefits	savings	net benefit
0 (2013/14)	208,000	240,000	34,000	67,000
1	208,000	240,000	34,000	67,000
2	208,000	240,000	34,000	67,000
3	208,000	240,000	34,000	67,000
4	208,000	240,000	34,000	67,000
5	208,000	240,000	34,000	67,000
6	208,000	240,000	34,000	67,000
7 (2019/20)	208,000	240,000	34,000	67,000
NPV	£1317,000	£804,000	£217,000	£514,000

Table 28 Annual costs and benefits for 1 additional lung transplant per year

7.6. Wider Economic Benefits

The previous section has described, and attempted, some quantification of the benefits from additional transplantation within NHS Scotland. However, QALYs do not capture all the benefits that may result. As the number of transplants increases, so do the number of survivors and the length of that survival. There is a growing literature on the impact, not just on the quality of life of these individuals but their ability to contribute to wider society through paid or unpaid employment. This is covered in more detail in section 2 of the report.

Of the 134 responses to the transplant recipient questionnaire, 22 cited returning to work as a positive impact from transplantation. The ability to resume work will depend on a number of factors including age, degree of illness prior to surgery, any complications after surgery, side effects from continuing medication, lack of income, family support, level of confidence, and psychological wellbeing. There may also be the opportunity for other family members, previously acting as carers, to re-enter the workforce.

8. Conclusions

The following conclusions and recommendations have been developed by the Reference Group and approved by the Commissioning Board.

8.1. Activity and capacity

With the growing rates of underlying disease and the potential for increased organ availability, it is almost certain that transplantation activity will continue to rise over the next six years.

8.1.1. Adult heart transplantation

Activity

The 2013/14 number of 19 transplants was more than double the activity level that it was any other year during the past decade. This was likely due to the increased level of referrals to the service, the increased waiting list and acuity of patients, as well as the increase in organ donation seen through the Scout programme. It was felt that this high level of activity was an exception, that the need for heart transplantation would remain steady, and that a forecast of 18 transplants per year by 2020 was reasonable.

Capacity

The current Scottish Advanced Heart Failure Service is commissioned to provide 12-15 heart transplants per annum. In 2013/14, the pressure of the 4 additional heart transplants over the commissioned capacity levels of the service was noted by the service and the hospital. Discussions will continue between NSD and NHS National Waiting Times Centre Board to review the activity that has increased slightly beyond commissioned levels.

8.1.2. Adult Congenital Heart Disease (ACHD) transplantation

Activity

With an increase in organ availability and an growing cohort of adults with complex congenital heart disease lesions who have had a number of interventions throughout their lifetimes, it is forecast that ACHD transplantation activity will increase from 2 in 2013/14 to 5 in 2019/20.

Capacity

Capacity for transplantation at Freeman Hospital is restricted in light of significant transplant growth over the past 10 years. The current capacity limit at Freeman Hospital for cardiothoracic transplant is 100 transplants per year (from across the UK); any more would have a detrimental effect on cardiac surgery. Increasing transplant activity and complexity has created pressures on ITU beds, recipient coordinators, and physician time for assessment and follow-up. Theatre space and surgical capacity are thought to be sufficient.

8.1.3. Paediatric heart transplantation

Activity

Paediatric heart transplantation activity is forecast to increase very slightly from 1 per annum to 2-4 per annum.

Capacity

The small increase in paediatric heart transplantation activity is unlikely to have a significant impact on capacity at Freeman hospital. However, section 8.1.2 outlines the capacity challenges for cardiothoracic transplantation at Freeman hospital in further detail.

8.1.4. Lung transplantation

Activity

Lung transplantation activity on Scottish residents has grown from 12 transplants in 2004/05 to 20 transplants in 2013/14. From 2012, it was felt that the use of Ex-Vivo Lung Perfusion (EVLP) as part of the DEVELOP-UK study may have had a positive impact on transplantation activity. The DEVELOP-UK study has now ended, and this may have an impact on reducing activity. Current activity for lungs is restricted by organ availability and capacity at Freeman Hospital. Despite the conclusion of DEVELOP-UK, with the forecast increased availability of organs, the service has predicted growth from 20 to 24 lung transplants per annum on Scottish residents.

Capacity

As noted above in section 8.1.2.

8.1.5. Adult renal transplantation

Activity

The two adult renal transplantation services forecast a significant increase (43.9%) in transplantation activity over the next six years, with a 40.1% increase in growth in deceased donor transplantation activity from 172 to 241 deceased donor transplants, and a 51.9% increase in living donor activity from 81 to 123 living donor kidney transplants over the next six years.

To facilitate this increase in activity, the living donation process will need to be streamlined to reduce inefficiencies in the pathway and to support the increasing number of people wishing to donate their kidneys. This will also be of benefit to the paediatric renal transplantation service. Novel Technologies in Organ Transplantation may also increase deceased donor organ usage in the future.

Capacity

The two services have recently been through a process of consideration for national designation and have identified the funding required to support the increased capacity within the two services.

Increased activity will have a significant impact on the capacity of both services, their supporting services (such as Histocompatibility and Immunogenetics and Clinical Apheresis), and the two hospitals providing the service (the new South Glasgow Hospitals Campus and the Royal Infirmary of Edinburgh). Despite this significant growth, making projections over the next six years has allowed time for the services, host Boards, and NSD to highlight this potential growth and plan to accommodate the increase in activity. Work to fully scope the feasibility of delivering against this level of growth will need to continue in the

future. If capacity is not available within the two transplantation units, then NSD would need to work with NHS Scotland to identify other provision for patients within the United Kingdom.

8.1.6. Paediatric renal transplantation

Activity

Over the last ten years, there has been a slight increase in the number of children being placed onto renal replacement therapy, from about 9pmp to 10pmp. Unless there is an unexpected increase in birth rates, paediatric renal transplant activity is predicted to increase from 6-8 per year to about 8-12 per year by 2020, with 4-6 per annum being deceased donor kidney transplants, and 4-6 per annum being living donor kidney transplants.

Capacity

The paediatric renal replacement therapy services, including the nationally commissioned paediatric renal transplantation service, are moving from the Royal Hospital for Sick Children (Yorkhill) to the new South Glasgow Hospitals Campus in summer 2015. This will allow for the further development of links with the adult renal transplantation service, which will also be relocated from the Western Infirmary to the new South Glasgow Hospitals Campus in 2015. There should be sufficient capacity for the paediatric renal transplantation service at the new hospital.

8.1.7. Adult liver transplantation

Activity

As a result of the high Scottish incidence of liver disease, the need for liver transplant will remain high. The largest limiting factors were the availability of organs and the allocation scheme. Despite the potential of Sofusbuvir for Hepatitis C patients and the potential impact of minimum alcohol pricing if this is legislated for in Scotland, as these will take a number of years to have a significant impact on liver transplantation activity, activity is forecast to increase by 37.9% from 95 in 2013/14 to 131 in 2019/20.

Capacity

As with adult renal transplantation, increased activity will have a significant impact on the capacity of the service, its supporting services, and the Royal Infirmary of Edinburgh which hosts the service. Despite this significant growth, making projections over the next six years has allowed time for the service, NHS Lothian and NSD to highlight this potential growth and plan to accommodate the increase in activity. Work to fully scope the feasibility of delivering against this level of growth will need to continue in the future.

The Royal Infirmary of Edinburgh has already undergone work to maximise efficiency within the pressing finance and capacity constraints. The liver and renal transplant services have recently been through LEAN processes, and the SPK and islet transplant services are currently undergoing these processes. Some very positive steps have been made to ensure that the services are as efficient as possible for their patients; that the use of scarce hospital capacity is minimised; and that unnecessary costs are avoided. This should go some way in helping support the growth in transplantation activity. While the service cannot currently fully commit to meeting activity levels in 2020, they will be able to deliver the activity levels forecast for the next three years and will review activity on an ongoing annual basis.

8.1.8. Simultaneous Pancreas-Kidney transplantation

Activity

The factor that would most impact on Simultaneous Pancreas-Kidney (SPK) and Pancreas-alone activity forecasts would be diabetes levels, rather than organ availability. As the prevalence of type 1 diabetes is not increasing, the number of patients with diabetes who have end stage renal failure has decreased. It is likely that activity will remain stable at 15 Scottish SPK transplants and 5 Northern Irish SPK transplants. The numbers for solid organ pancreas-alone transplant were very difficult to predict, as there is only one every 2-3 years.

Capacity

As there is not forecast to be an increase in activity for this service, there should not be a need to develop further the capacity of the SPK service.

8.1.9. Islet transplantation

Activity

The Royal Infirmary of Edinburgh provides a nationally commissioned service for Scottish patients, as well as a service for Northern Ireland. If pancreas availability develops, as referrals from across Scotland increase into the service and the waiting list increases as a result, activity is projected to rise from 11 to 30 islet transplants per annum on Scottish residents and 2 to 5 islet transplants per annum on Northern Irish patients.

Capacity

The service is commissioned to provide up to 36 transplants per annum, and the associated capacity is in place for this level of activity. As a result, an increase in islet transplantation activity to 30 per annum will not require additional investment in islet transplantation capacity.

The islet isolation laboratory provided by the Scottish National Blood Transfusion Service (SNBTS) is unable to provide a 24/7/365 rota that is compliant with the European Working Time Directive. As a result, options are being considered by SNBTS on the best model of future islet isolation provision, which will be submitted to NSD.

8.1.10. Service sustainability

In these highly specialised areas and alongside the increases in transplant activity, the need to ensure the future sustainability of all the transplant services is crucial. *Support should be offered to the services for medical training, workforce development, and retention. With ageing consultant workforces, it has also been recommended that, when necessary, support should be offered for succession planning through proleptic appointments.*

It is important to maintain public confidence in organ donation and transplantation, in order to sustain levels of donation necessary to provide the increases in transplantation. *The transplant services and public organisations, such as Organ Donation Scotland, should continue to ensure that public awareness and confidence are maintained.*

8.1.11. Supporting services

Organ retrieval

Organ retrieval is provided in Scotland by the Scottish Organ Retrieval Team (SORT), which is commissioned by NHSBT. SORT is hosted by NHS Lothian and is a multi-organ service, with abdominal retrievals led by the NHS Lothian team and cardiothoracic retrievals led by NHS National Waiting Times Centre Board. NHS Lothian also hosts the team of theatre practitioners (scrub and organ preservation). SORT provides continuous coverage for organ retrieval throughout Scotland, as well as second on-call backup for other UK retrieval teams.

Organ retrieval services in Scotland have undergone greater changes in recent years than in the UK as a whole. Scotland has had historically low levels of organ retrieval, which is now rising rapidly to match the rest of the UK. This increase in retrieval activity has had serious impact on the transplant services in the host hospitals. At the Royal Infirmary of Edinburgh, significant pressures have been placed on rotas within Anaesthetics, Theatres and Critical Care Directorate, who are also working to meet the demands of significant increase in theatres activity at the RIE site, which includes the interdependent national transplant programmes. The Golden Jubilee National Hospital has also been significantly impacted by these increases in activity.

The interdependencies between organ retrieval and transplantation are clear. Increases in organ retrieval will continue to have a significant effect on the transplantation services in the associated hospitals.

Histocompatibility and Immunogenetics

The Reference Group has recognised the importance of H&I and its impact on transplantation processes, and have recommended that the H&I costs associated with transplantation should be supported. *The fixed and variable elements of the Histocompatibility and Immunogenetics service in Scotland (SNBTS and NHS Greater Glasgow and Clyde) should be added to the profiles of the commissioned transplantation services to ensure that timely support can be provided.*

Manpower

It is essential to maintain qualified and competent staff at all levels to enable active consultant-level on-call and laboratory scientific on-call rotas. The manpower structure in Glasgow is under review by NHS GG&C with regard to a deputy for the Consultant Clinical Scientist (Head of Laboratory), a position which exists in Edinburgh.

Equipment and facilities

Both the Edinburgh and Glasgow H&I laboratories currently have adequate equipment, although investment in new hardware may be required in the future if new methodologies are introduced. The Glasgow H&I laboratory is part of a Managed Service Contract, which provides the opportunity for ensuring adequate and appropriate equipment is in place. Both laboratories could accommodate increased testing with their current equipment. Any changes to equipment may have a consequent impact on staffing capacity and this would need to be reviewed.

The Glasgow laboratory has adequate laboratory space. There is limited space available for the Edinburgh laboratory, however, which has the potential to limit the expansion of the services offered to support transplantation (e.g. extra Luminex testing to define C' fixing antibodies).

Information Technology

All developments within Histocompatibility and Immunogenetics must be supported with robust IT systems to enable safe and effective communications with the transplant teams. *It is recommended that the H&I services work with the provider NHS Boards to ensure that robust IT systems are in place which have the appropriate linkages with other relevant IT systems involved in the care of patients.*

8.1.12. Developments

There are a number of developments which may impact on the demand, availability, and capacity of the nationally commissioned transplantation services.

Finance

In light of the financial situation within the public sector, there can be no new developments for any of the specialist services including transplantation. NSD should liaise with each transplantation service and review activity on an annual basis, bearing in mind the activity forecasts set by the Reference Group. *Increased transplantation activity will have to be at least partially funded by increased efficiencies across the national services, including the transplantation services.*

Research

It is essential that all transplantation services continue to seek opportunities for research and development, to ensure that the Scottish transplant services are able to continue to innovate in line with the transplantation services across the UK. *Where links remain informal, relationships with the universities should be formalised to support the development and sustainability of the transplantation services.*

Potential designation of new national services

Interests have been expressed in the national designation of new Scottish transplantation services, and extensions to the designation of existing services. *These services are invited to start scoping and feasibility work which may potentially lead to the development of proposals for consideration of national designation by the National Specialist Services Committee (NSSC).*⁹⁸

The NSSC consideration process is robust and involves a thorough assessment of each of the proposals from applicants, which are required to meet the NSSC's criteria and clearly demonstrate that the advantages and benefits of undertaking these services in Scotland outweigh the costs and disadvantages. The NSSC would also ensure that these developments have the support of patients, the voluntary sector, and clinical communities.

⁹⁸ National Services Division. The national designation process. Available from: <http://www.nsd.scot.nhs.uk/about/nssc.html>

Fulminant hepatic service and paediatric liver transplant service

NHS Lothian has expressed an interest in the national designation of the existing fulminant hepatic failure service, as an extension to the current liver transplantation service. NHS Lothian is currently the sole-Scottish provider of this service, which is provided on a non-nationally commissioned basis for residents of Scotland.

NHS Lothian has informed NSD that the re-provision and associated co-location of the Royal Hospital for Sick Children with the Royal Infirmary of Edinburgh will bring about much of the required infrastructure for a new paediatric liver transplantation service. This service is currently provided for Scottish children with good outcomes in Birmingham, King's College and Leeds.

ACHD and lung transplantation

Adult Congenital Heart Disease (ACHD) transplantation and lung transplantation services are currently commissioned by NSD and provided for people who reside in Scotland by Freeman Hospital in Newcastle. NHS National Waiting Times Centre Board (the Golden Jubilee National Hospital) has expressed an interest in providing transplantation for ACHD and lungs for residents of Scotland. In light of the growing and ageing cohort of people with complex ACHD lesions, it may be possible that the growth in the number of people with ACHD requiring a heart transplant would ensure a sufficient minimum caseload for a viable Scottish programme.

Freeman Hospital, which provides both services, has provided a good quality service with good outcomes and, despite the need for Scottish residents to travel to Newcastle, these two services both have on the whole been well received by patients and referrers.

8.2. Service specifications

8.2.1. Service definitions

Service specifications and definitions will be developed by NSD to take into consideration all of the conclusions and recommendations that are accepted by the NSSC.

8.2.2. Quality indicators

The NHS Scotland Healthcare Quality strategy highlights the importance of 'making measurable improvement in the aspects of quality of care that patients, their families and carers and those providing healthcare services see as really important'.

A significant amount of data is collected and submitted by all transplantation services for the purposes of clinical audit. For transplantation, the majority of reported quality indicators relate to survival based indicators for the graft and transplant recipient. Survival is clearly of primary importance post-transplantation, however, as outlined in the Healthcare Quality Strategy statement above, measurable improvement needs to be made in areas which patients, families, carers, and healthcare providers see as really important.

Bearing this in mind, the Commissioning Transplant to 2020 Reference Group considered their approach to audit and quality improvement, and defined a number of survival and non-survival based quality indicators which are outlined below (in draft):

Generic indicators

Potential generic indicators informed by the Reference Group

- Referrals by NHS Board of residence within expected range
- New outpatient assessments occur within 12 weeks
- Survival from listing
- Total cold-ischaemia times benchmarked against UK services
- Transplantation procedure complication rates
- Risk-adjusted one-year graft survival rates within UK 95% confidence intervals
- Risk-adjusted one-year patient survival rates within UK 95% confidence intervals
- Transplant related readmission rate within 3 months
- Re-transplantation rates
- Different for each service:
 - Health Related Quality of Life
 - Patient Reported Outcome Measures

Potential generic indicators informed by patient feedback

The following indicators are based upon patient feedback received to date through the patient experience survey and patient focus groups:

- All patients / living donors are proactively offered access to psychological support (happens in GJNH and Freeman, is within Lothian profile, would be an increase in Glasgow)
- All patients receive individualised discharge plans
 - The transplant services should offer all transplant patients the opportunity to jointly create care plans which can be further developed by local services.
 - These care plans should support the development of local aftercare (e.g. psychology, diabetes control) and local tests (e.g. skin surveillance, skeletal checks).

Service specific indicators

Advanced heart failure (heart transplantation)

- Prospective transplant recipients receive an assessment that identifies any emotional distress, behavioural disturbance, or social problems
- Transplant recipients receive an assessment that identifies any emotional distress, behavioural disturbance, or social problems
- Prospective and actual transplant recipients with psychological problems are offered evidence-based psychological interventions
- People receiving treatment for emotional distress and behavioural disturbance have their response to treatment recorded at each treatment session

Lung transplantation

- CQUIN indicators are in the process of being developed and will be considered for usage to assess the quality of service for Scottish patients in the future

Paediatric and adult renal transplantation

- Pre-emptive transplant rate
- Pre-emptive live donor transplant rate
- Annual rate pmp live donor pair transplanted within 18 weeks of referral
- Annual rate pmp altruistic / paired transplant performed within 8 weeks of match
- Creatinine and eGFR at 1 year post transplant
- Readmission rates within 3 months for:
 - CMV infection
 - Biopsy proven graft rejection

Islet transplantation

The following indicators are collected and benchmarked nationally:

- Insulin independence within or above all centre average (90 minute C-peptide ≥ 50 pmol/l)
- Reduction in annual rate of severe hypoglycaemic events for patients transplanted

Liver transplantation

- Quality performance indicators are being developed that relate to patient experience

Histocompatibility and Immunogenetics (H&I)

- Maintenance of European Federation for Immunogenetics accreditation
- Maintenance of UKAS, CPA Ltd accreditation
- Acceptable performance in NEQAS schemes relevant to testing provided for transplantation
- Assess donor HLA typing errors (target is zero errors)

It is recommended that all of these quality indicators are measured, reported in future annual reports, and acted upon.

8.2.3. Approaches to machine organ perfusion

Based on the current available evidence, at present no novel technology for organ transplantation can be recommended for a national scale implementation. The NHSBT Novel Technologies for Organ Transplantation (NTOT) group have concluded that, whilst no technologies were ready for a UK-wide roll out, Ex-Vivo Lung Perfusion (EVLP) and Normothermic Regional Perfusion (NRP) were appropriate for further UK service evaluation. NHS Blood and Transplant have agreed to fund a short-term service evaluation of NRP (to be undertaken within the current financial year). Work is underway to develop service evaluation protocols for both NRP and EVLP.

Changes in the NHSBT National Organ Retrieval Service system (logistics and personnel) and financial planning should be considered in the next three years to accommodate the likely changes in preservation and perfusion technologies. The NHSBT NTOT group will reconvene as a short term working party in three years to evaluate the additional data and make formal recommendations for 2020. The NTOT group expect that these technologies will be introduced into clinical practice across the UK within the next 5 years. It will ultimately be for NHS Scotland and the Scottish Government, as the sponsors of the National Organ

Retrieval Service commissioned by NHSBT and the sponsors of transplantation, to consider and potentially approve the use of these technologies. *NHS Scotland should be aware that these Novel Technologies in Organ Transplantation will potentially impact significantly on the costs of the donation and transplantation process.*

8.2.4. Approaches to the care of patients

Extra-corporeal Membrane Oxygenation (ECMO) and Ventricular Assist Devices

As noted above, the 2013/14 level of heart transplantation activity at 19 transplants was more than double the activity level that it was any other year during the past decade. Over the next six years, it is forecast that heart transplantation activity will grow from 16 cases in 2014/15 to 18 cases in 2019/20. As it is expected that the length of the heart transplant waiting list and organ availability will not change significantly from those in 2013/14, it is appropriate to use 2013/14 to assess activity expectations on ECMO and VAD usage.

The cost impact of increased heart transplantation activity in 2013/14 was offset by a reduction in the use of long-term VADs (2 used in 2013/14), which have a high variable cost per case. This is likely to continue over the next five years. With forecast increased organ availability, the requirement for long-term Ventricular Assist Devices should remain low in line with reductions in the average time between listing for heart transplantation, and the heart transplant. It is expected that short-term VAD activity should remain at around 15 cases per annum. Post-operative cardiac ECMO usage should remain at a similar level to 2013/14 at around 10 per annum.

Outpatients, wards, theatres and critical care

The increases in activity across transplantation programmes will create additional pressure for the clinic, ward, theatre and critical care environments within the transplant units. These will be particularly pronounced in the units where the largest increases in activity are forecast (i.e. the Royal Infirmary of Edinburgh and the new South Glasgow Hospital Complex). *It is recommended that these two units continue to plan for the impact of growth in transplantation activity on their hospitals.*

Patient information

The consultation with transplant recipients has identified that patients would like to receive more information about:

- assessment (how decisions are made)
- waiting list (updates, 'false calls')
- life after transplant (side effects of medications)

NHS Inform is Scotland's national health information service which provides a co-ordinated, single source of quality assured health and care information for the people of Scotland. This service is provided by NHS 24. *It is recommended that the transplantation services work with the voluntary sector and NHS 24 to develop the existing transplantation sections of NHS Inform. This would be in addition to the information already provided by the individual services and would offer a central online resource for patients, family, carers, and friends. As part of this exercise, consideration should be provided to developing an online web forum to*

support those who are referred, assessed, or on the waiting list for transplant, in addition to those who have received transplant and are inpatients in the transplant units, or have been discharged and are receiving their aftercare.

Patient feedback

The feedback received from the patient consultation has been invaluable. In order to deliver person-centred care, patient and voluntary sector feedback is crucial to the design of the transplant services in the future. *All of the nationally commissioned transplantation services should work with living donors, patients and the voluntary sector to seek feedback to:*

- *Continually improve the quality of service for their patients.*
- *Develop patient reported outcome measures (PROMs)*

Support for the mental health needs of patients and donors

The strongest theme that came out of the patient experience survey and focus groups was the importance of psychological support at all stages of the transplantation pathway. A number of anxieties raised related to the provision of information, and as a result *the transplant services should work to develop patient information to reduce anxiety and better support patients. Additionally, better signposting to voluntary sector organisations and patient associations/peer support groups will support individuals who need or have received a transplant.*

The transplantation services should work to ensure that all patients are offered appropriate psychological support throughout their experience of the transplant service. Patients and living donors who require psychiatric input should also have access to a psychiatric assessment.

Promotion of transplantation services to referrers

In order to ensure that patients continue to be referred appropriately in a timely fashion to the transplantation services from across Scotland, *it is essential that the transplant services continue to promote their services to referrers and remind referrers of the appropriate thresholds for referral.*

8.2.5. Follow-up and shared care arrangements post-transplant (i.e. aftercare)

As the transplantation services are all provided centrally within one or two sites, the majority of patients will reside in NHS Boards out with the national transplantation unit. This presents challenges to the local care of patients after transplant. The following conclusions and recommendations have been developed in order to support people to be managed safely, as locally as possible.

Care planning

The transplant services should offer all transplant patients the opportunity to jointly create care plans which can be developed by local services. These care plans should support the development of local aftercare (e.g. psychology, diabetes control) and local tests (e.g. skin surveillance, skeletal checks).

Follow-up

It is recommended that where possible and viable, patients are followed-up locally through outreach clinics in order to reduce the need to travel for patients. The services should liaise with NHS 24 Scottish Centre for Telehealth to explore options for the usage of telemedicine.

PatientView

Renal PatientView was launched as a national project in 2005 and was made available to all UK renal units following positive feedback. Currently 90% of UK renal units are involved. The project was renamed to PatientView in 2013, following an expansion to services beyond renal (now includes resources for Inflammatory Bowel Disease and Diabetes). PatientView allows patients secure access to blood tests, clinic letters and medicines from their healthcare records, along with information about diagnosis and treatments. This allows patients more involvement and greater control over their own healthcare, which promotes feelings of empowerment and independence.

Feedback from the Commissioning Transplant to 2020 patient experience questionnaire and focus groups indicated that kidney transplant recipients were very satisfied with the project and that recipients of other transplanted organs were very interested in PatientView being expanded to allow them access as well. It was felt that this would be particularly helpful for results from regular investigations, such as blood tests.

Initial discussion held with PatientView managers has determined that it would be possible (and welcome) to expand the project to include all transplant patients. Systems already in place for renal patients could be used, as PatientView uses CHI numbers for data collection. There would be a small cost implication involved in establishing this project, as well as in developing infrastructure to connect to the local health boards. PatientView has indicated that other services are interested in using PatientView for their patients, so there is potential for costs to be shared. *It is recommended that PatientView be expanded to all transplant patients, as the impacts on patient empowerment and well-being would be significant.*

Information for General Practitioners and referrers

Information provided by the transplant units is used to support the local management of care by General Practitioners and referrers, in allowing GPs and referrers to continue the patient's care and management following their discharge from hospital or outpatient assessment. To support this process, accurate and timely records of assessment, care, and treatment are required:

- *In producing discharge information for patients, SIGN 128 should be followed⁹⁹ and Immediate Discharge Documents and Discharge Summaries should ideally be sent out to GPs / referrers on the day of discharge, and within a week of the patient's discharge date respectively.*
- *Additionally, outpatient clinic letters and admin letters should be dispatched within 2 weeks of the clinic date.*

⁹⁹ Healthcare Improvement Scotland. SIGN 128 (2012). The SIGN discharge document. Available from: <http://www.sign.ac.uk/pdf/sign128.pdf> [Accessed 21 January 2015].

Management of medicines post-transplant

Local initiatives to manage risks

A range of local initiatives have been recommended by the Reference Group to try to mitigate the risk of inadvertent branded prescribing, including:

- *The inclusion of alerts in Health Board bulletins*
- *Ensuring patients understand the importance of staying on a consistent brand, for example through use of patient-alert cards*
- *Targeted guidance to prescribers and pharmacists in primary care*
- *The inclusion of on-screen alerts to GPs at the point of prescribing using the 'Scriptswitch' software. There are also in-built warning in the EMIS and Vision systems*
- *The inclusion of on-screen alerts to pharmacists at the point of dispensing using the Cegedimrx Nexphase and Pharmacy Manager system, Pharmasys UK and Rx Systems*
- *Practice based pharmacists checking GP-held records to ensure branded prescribing*
- *Analysis of prescribing data to identify where generic prescriptions are still being issued (it is possible to interrogate data down to individual patient/prescriber level)*

National initiatives to mitigate risks

The Scottish Government has agreed to send out a formal letter to all prescribers and dispensers in Scotland to raise awareness and inform these groups of the risks of the inadvertent switching of medicines from branded to generic products.

Repatriation of prescribing and dispensing

The Reference Group endorsed the pharmaceutical subgroup's view that, whilst the use of homecare does have the potential to ensure consistent branded prescribing, given the risks and other consequences of this approach, it would be disproportionate to adopt a repatriation policy in Scotland on safety/quality grounds.

It is acknowledged that repatriation has the potential to deliver cost-savings, and it is recommended that NSS Procurement Commissioning and Facilities (National Procurement) continue in discussions with Scottish Government on alternative options to access those savings within existing care pathways.

8.3. Public health and wider societal impacts of transplantation

This review assessed evidence on the impact of transplantation on donor recipients, both in terms of long-term survival rates and effect on physiological and physical wellbeing. It has been shown that the impact of transplantation on recipients' overall quality of life is considerable. While there appears to be some variation by organ type, the improvement tends to be strongest in the dimensions most affected by physical health, with more modest improvements in psychosocial areas.

Receiving a transplant allows a person to regain independence, such as through return to employment or education, strengthening social and family relationships, becoming pregnant, or participating in sport. Factors associated with a return to work include better functional ability, higher education, fewer rejection episodes, shorter time on waiting list, and pre-

transplant employment. Children are also better able to return to and succeed in schooling after receiving a transplant. As the goal of transplantation is not simply graft survival but to also significantly improve patients' ability to function, health related and overall quality of life are recognised as important factors.

Despite positive results in a number of areas, however, overall quality of life after organ transplant still appears lower than that experienced by patients before developing organ failure and that of the healthy general population. This discrepancy may be related to medical complications after the operation, psychological difficulties, or psychosocial adjustments. It is well evidenced that the psychological well-being of transplant recipients is dependent upon a number of factors, which include original disease aetiology, psychiatric history, educational level, and post-transplant support (from carers, family, health workers, and peers). It has also been found that kidney transplant recipients have better psychological well-being than those who are on dialysis, proving that the transplant itself can be beneficial. *This should be supported by other areas of support offered to patients. Certain strategies, such as improved psychological and social support, have been highlighted as having positive impact on improving the quality of life of transplant recipients.*

8.4. Health and social care resource impact analysis

Organ transplantation is an expensive, highly technical process, which involves a range of health professionals and resources and has the potential to transform the lives of many patients and families. Using QALY values from literature and applying the standard DH valuation of £60,000 per QALY suggests that NPVs for this programme of work are positive (i.e. the value of the benefits outweighs the value of the costs).

Costs	Benefits
Total cost of service : including <i>inter alia</i> staff costs, theatre costs, lab costs, pharmaceuticals & follow up care	Additional life years and quality of life for recipients: increasing number of transplant survivors
Incremental cost associated with additional activity	Additional QALYs => increased social interaction, more employment => increase in economic activity, reduction in welfare payments
Possible service redesign: Potential capital investment for new technologies	Increase expertise in transplantation techniques/ expansion of service
Costs to both donors and recipients in terms of stress, anxiety, psychological impacts	Increase in altruism => improved societal well being

Table 29 Main costs and consequences of organ transplantation

9. Summary of recommendations

	Action	Responsible
R1	To facilitate the increase in activity, the living donation process will need to be streamlined to reduce inefficiencies in the pathway and to support the increasing number of people wishing to donate their kidneys.	Renal transplant service
R2	Support should be offered to the services for medical training, workforce development, and retention. When necessary, support should also be offered for succession planning through proleptic appointments.	NSD
R3	The transplant services and public organisations, such as Organ Donation Scotland, should continue to ensure that public awareness and confidence are maintained.	All transplant services / Scottish Government
R4	The fixed and variable elements of the Histocompatibility and Immunogenetics service in Scotland (SNBTS and NHS Greater Glasgow and Clyde) should be included in the profiles of the commissioned transplantation services, in order to ensure that timely support can be provided.	NSD / SNBTS / NHS GGC
R5	It is recommended that the H&I services work with the provider NHS Boards to ensure that robust IT systems are in place which have the appropriate linkages with other relevant IT systems involved in the care of patients.	H&I services
R6	Increased transplantation activity will have to be at least partially funded by increased efficiencies across the national services, including the transplantation services.	All transplant services
R7	Where links remain informal, relationships with the universities should be formalised to support the development and sustainability of the transplantation services.	All transplant services
R8	Those services which have expressed interest in the national designation of new Scottish services and extensions to designation of existing services are invited to start scoping and feasibility work which may potentially lead to the development of proposals for consideration of national designation by the National Specialist Services Committee (NSSC).	NHS Lothian / NHS NWTCB
R9	Service specifications and definitions will be developed by NSD to take into consideration all of the conclusions and recommendations that are accepted by the NSSC.	NSD
R10	All of the quality indicators (7.2.2) should be measured, reported in future annual reports, and acted upon.	All transplant services

R11	NHS Scotland should be aware that the Novel Technologies in Organ Transplantation will potentially impact significantly on the costs of the donation and transplantation process.	NHS Scotland
R12	The transplant units in the Royal Infirmary of Edinburgh and the new South Glasgow Hospital Complex should continue to plan for the impact of growth in transplantation activity in their hospitals.	NHS Lothian / NHS GGC
R13	It is recommended that the transplantation services work with the voluntary sector and NHS 24 to develop the existing transplantation sections of NHS Inform. This would be in addition to the information already provided by the individual services and would offer a central online resource for patients, family, carers, and friends. As part of this exercise, consideration should be provided to developing an online web forum to support those who are referred, assessed, or on the waiting list for transplant, in addition to those who have received transplant and are inpatients in the transplant units, or have been discharged and are receiving their aftercare.	All transplant services
R14	All of the nationally commissioned transplantation services should work with living donors, patients and the voluntary sector to seek feedback to: - Continually improve the quality of service for their patients - Develop patient reported outcome measures (PROMs)	All transplant services
R15	The transplant services should work to develop patient information to reduce anxiety and better support patients. Additionally, better signposting to voluntary sector organisations and patient associations/peer support groups will support individuals who need or have received a transplant.	All transplant services
R16	The transplantation services should work to ensure that all patients are offered appropriate psychological support throughout their experience of the transplant service. Patients and living donors who require psychiatric input should also have access to a psychiatric assessment.	All transplant services
R17	It is essential that the transplant services continue to promote their services to referrers and remind referrers of the appropriate thresholds for referral.	All transplant services
R18	The transplant services should offer all transplant patients the opportunity to jointly create care plans which can be developed by local services. These care plans should support the development of local aftercare (e.g. psychology, diabetes control) and local tests (e.g. skin surveillance, skeletal checks).	All transplant services
R19	It is recommended that where possible and viable, patients are followed-up locally through outreach clinics in order to reduce the need to travel for patients. The services should liaise with NHS 24	All transplant services

	Scottish Centre for Telehealth to explore options for the usage of telemedicine.	
R20	It is recommended that PatientView be expanded to all transplant patients, as the impact on patient empowerment and independence would be significant.	NSD / All transplant services
R21	In producing discharge information for patients, SIGN 128 ⁹⁹ should be followed and Immediate Discharge Documents and Discharge Summaries should ideally be sent out to GPs / referrers on the day of discharge and within a week of the patient's discharge date, respectively. Additionally, outpatient clinic letters and admin letters should be dispatched within 2 weeks of the clinic date.	All transplant services
R22	A range of local initiatives have been recommended by the Reference Group to try to mitigate the risk of inadvertent branded prescribing, including: • The inclusion of alerts in Health Board bulletins • Ensuring patients understand the importance of staying on a consistent brand, for example through use of patient-alert cards • Targeted guidance to prescribers and pharmacists in primary care • The inclusion of on-screen alerts to GPs at the point of prescribing using the 'Scriptswitch' software. There are also in-built warning in the EMIS and Vision systems • The inclusion of on-screen alerts to pharmacists at the point of dispensing using the Cegedimrx Nexphase and Pharmacy Manager system, Pharmasys UK and Rx Systems • Practice based pharmacists checking GP-held records to ensure branded prescribing • Analysis of prescribing data to identify where generic prescriptions are still being issued (it is possible to interrogate data down to individual patient/prescriber level)	All transplant services / NSS PCF (National Procurement)
R23	The Scottish Government has agreed to send out a formal letter to all prescribers and dispensers in Scotland to raise awareness and inform these groups of the risks of the inadvertent switching of medicines from branded to generic products.	Scottish Government
R24	NSS Procurement Commissioning and Facilities (National Procurement) should continue in discussions with Scottish Government on alternative options to access cost savings within existing care pathways.	NSS PCF (National Procurement)
R25	The physical benefits of transplantation should be supported by other areas of support offered to patients. Certain strategies, such as improved psychological and social support, have been highlighted as having positive impact on improving the quality of life of transplant	All transplant services

Commissioning Transplantation to 2020

	recipients.	
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