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Queensland
Government
Queensland Health

Selected Specialist Services

Direction Statement

2001-2010

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Foreword

This directions statement recognises the major contribution of super-specialist services provided by Queensland Health. These services represent a significant component of acute care services and helps to ensure that a well-balanced health care system is provided to all Queenslanders.

The *Selected Specialist Services – Direction Statement 2001-2010* describes a range of selected specialist services which are positioned at the complex end of the comprehensive health care system provided by Queensland Health.

In the main, super-specialist services provide for a relatively few number of patients, involve a high level of clinical complexity, use a significant element of technology, and have a high cost per episode of care. As a result, these services are located in only a few sites within the state.

The identification of the services included in the *Selected Specialist Services – Direction Statement 2001-2010* is consistent with national and international trends. Broad directions for the development of these services are provided to ensure equity of access for all Queenslanders requiring these services.

The *Selected Specialist Services – Direction Statement 2001-2010* is a "living" document that will be reviewed on a regular basis as new evidence becomes available. This will ensure that planning for specialist services remains responsive to changes in patient needs and developments in clinical practice.

I am pleased to endorse this directions statement as a platform for the planned development of selected specialist services across Queensland during the decade.

This document is a restricted release for the purpose of internal planning for health services for Queensland Health
August 2001

Introduction

Queensland Health seeks to ensure that all Queenslanders have optimum access to the full range of health services it provides. Super-specialist health services provide the most complex aspects of acute health care for the people of Queensland and are an essential element of a comprehensive, well-balanced health care system.

The intention of the *Selected Specialist Services – Direction Statement 2001-2010* is to facilitate the development and maintenance of the highest possible standard of care that can be delivered, within resources, to all Queenslanders requiring services of a super-specialised nature.

This document is a replacement document for the Queensland Health *Selected Tertiary Referral Services Plan for 2001* published in December 1994. In the 1994 document, the term "tertiary" was used to describe the selected specialised services. However, the term "tertiary" currently has many different uses[1]. Therefore, in this document the term "tertiary" has not been used. The use of role delineation terminology[2] has also been avoided to enhance clarity.

As a guide, super-specialist services provide for a relatively few number of patients with a high cost per patient episode. These services are staffed by clinicians with very specialised training, involve a high level of clinical complexity, require specialised facilities and equipment and use a significant element of technology. As a result, these services are located in only a few sites within the state.

As a way of classifying the selected specialist services for this document, four sections, distinguished by two criteria, were identified:

- whether the service is of a ***stand alone*** type or is at the ***complex end of a continuum*** of services
- whether the expected volume of patients plus the nature of the facilities required will justify only one ***state-wide service*** for a population of 3.6 million or ***zonal services*** for a notional population of 1 million people.

This document contains broad directions for the development of selected specialist services that should be pursued by Queensland Health to meet the anticipated needs of Queenslanders to 2010.

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[1] Alternative uses of the term "tertiary" include:

- as a description for "super specialist" services
- as the third part of the continuum primary, secondary and tertiary health services
- as the third level of hospital services with the first being non-specialised, the second being general specialists and the third being any sub-specialty service.

[2] For example, level 5 and level 6. Queensland Health, *Guide to the Role Delineation of Health Services*, 1994

The *Selected Specialist Services – Direction Statement 2001-2010* has been developed through an extensive consultation process and draws on the expertise of local senior clinicians and administrators. It also makes reference to the evidenced-based literature and includes an analysis of available health services data. Those contributing to this document are acknowledged in Appendix 1.

It is acknowledged that certain high cost and/or complex health services and technologies are not included in this paper. These will be, or are, the subject of separate Queensland Health planning processes and may be included in future updates of this document.

The planning and provision of health services must be a dynamic process which ensures that services have the flexibility to respond to changing needs and practices. For this reason, the *Selected Specialist Services – Direction Statement 2001-2010* is a living document that will be reviewed on a regular basis.

Summary of broad directions for service development

CLINICAL GENETICS SERVICES

- That the current state-wide model of providing clinical genetic services in Queensland, which is consistent with contemporary practice, continue.
- That all clinical genetic services be clinically linked with the state-wide clinical genetics service in Brisbane.
- That an expert group be established to determine referral criteria to ensure appropriate and equitable access to all Queenslanders.

RENAL TRANSPLANTATION SERVICES

- That the Princess Alexandra Hospital remain the sole provider for adult renal transplantation services.
- That if the transplantation rate increases to above 120 transplants per annum, the service framework should be reviewed to determine options for a second service.
- Given the low children's renal transplant rates, a single clinical team, with an appropriate level of trained support staff (ie nursing, allied health), should provide adult and children's renal transplant services in Queensland.
- That the clinical team currently providing services at the Princess Alexandra Hospital and Mater Children's Hospital, continue to provide adult and children's renal transplant services for Queensland.

LIVER TRANSPLANTATION SERVICES

- That the Princess Alexandra Hospital and the Royal Children's Hospital continue to be the sole providers of liver transplantation services for Queensland.
- That if the liver transplantation rate increases to above 60 transplants per annum, the service framework should be reviewed to determine options for a second service.

HEART AND LUNG TRANSPLANTATION SERVICES

- That the Queensland Heart and Lung Transplant Unit (QHLTU) at The Prince Charles Hospital continue to provide heart, lung and heart + lung transplantation services through the two service units.
- That these service units continue to be recognised as leaders in the management of the severe end of cardiac disease and lung/pulmonary vascular disease, developing into 'end-stage heart or lung disease management centres' rather than purely transplantation units.
- That babies requiring transplantation services (heart, lung) continue to be referred to the Royal Children's Hospital in Melbourne.

HAEMOPHILIA SERVICES

- That the current model of a state-wide haemophilia centre with outreach services continue.
- That there be movement towards full availability of recombinant products from the existing combination of approximately 35 per cent recombinant products and 65 per cent plasma derived products.

BURNS SERVICES

- That the Royal Brisbane Hospital and the Royal Children's Hospital continue to be the hospitals providing a single state-wide service for treatment of patients with burns injuries.
- That outreach services, through the use of tele-medicine networks, be developed for remote patients from Brisbane.

HAEMOPOIETIC STEM CELL TRANSPLANT SERVICES

- That all hospitals that do meet the AHMAC caseload recommendations for haemopoietic stem cell transplantation continue to provide this service.
- That all hospitals that do not meet the caseload considerations be reviewed in terms of safety and quality of the services provided.

ADULT CYSTIC FIBROSIS SERVICES

- That the coordinated development of the two state-wide specialised adult cystic fibrosis centres continue.
- That staff in other facilities are systematically educated on the provision of follow-up care for patients with adult cystic fibrosis.

NEONATAL SERVICES

- That the current service configuration with three Level III units having zonal responsibility be supported for continued clinical effectiveness.
- That the expertise of specialised neonatal paediatricians in larger units continue to be supported to provide the basis for a network, with regionalised services being well-linked.
- That the number of births in the Southern Zone be monitored (particularly in view of the services provided to babies born in northern New South Wales) to assess the need for an additional Level III unit.
- That the zonal networks be strengthened through identification and documentation of guidelines for:
  - transferring babies in utero and following delivery into a higher level unit
  - transferring babies back to district hospitals.
- That the role of hospitals with Level III and Level II nurseries be clarified and clearly documented.

CARDIAC SERVICES

- That prompt and appropriate revascularisation, by an appropriate technique, aiming for a ratio of 60:40 of percutaneous transluminal coronary angioplasty (PTCA) and coronary artery bypass graft (CABG), be provided.
- That the availability of diagnostic cardiac angiography within the public sector increase toward relevant guideline rates.
- Given the rapid advances in technology in this area, that these rates be reviewed in two years.
- That, as the provision of implantable cardioverter defibrillator (ICD) services with trained electrophysiologists is considered to be an essential component of comprehensive specialist cardiac care services, consideration be given to redistributing the workload between the Prince Charles Hospital and the Princess Alexandra Hospital rather than increasing the number of ICDs substantially.
- That an ICD service in the Northern Zone, is not indicated at present, and should be considered as part of longer term planning if demand changes.

Section 1: Whole of State Services, Stand Alone Services

CHAPTER 1: CLINICAL GENETICS SERVICES

Background

Clinical genetics primarily provide services for individuals and families with or at risk of heritable genetic disorders. This covers a spectrum of both rare monogenic and multifactorial disorders. There are over 6000 known genetic disorders.

It is estimated that approximately 50 per cent of the Australasian population are effected by a health problem with a genetic basis during their lifetime, while one in 20 persons are either wholly or partially effected in the first twenty years of life. Approximately 30 per cent of paediatric patients have an illness of a genetic basis and 28 per cent of all infant deaths are due to genetic factors. It is also estimated that 50 per cent or more of miscarriages are due to chromosomal disorders (N.S.W. Genetic Education Program, 2000).

Research into human genetics has been accelerated by the Human Genome Project (HGP). The publication of the human genome on the World Wide Web in February 2001 has made available data from the largest publicly funded multinational research collaboration. New molecular technology developed from the HGP now permits rapid analysis and identification of a growing number of genetic disorders and diseases, many of which have an environmental component. Common health problems such as coronary heart disease, hypertension, diabetes mellitus and many cancers will in the future fall within the scope of genetic testing. Developments in prenatal screening using maternal serum will also expand prenatal screening opportunities, while carrier screening for individuals and families at risk will assist parents in preconception planning. This opens the door to potentially better primary and secondary preventative health care and new therapeutic interventions such as gene therapy (Human Genome Project, 2000; Department of Human Services, 1996; The Royal College of Physicians of London, 1996 and 1998).

The services provided by a clinical genetics service can range from a single consultation for diagnosis and genetic counselling to more complex processes involving clinical and laboratory investigations of the patient and other family members. Clinical genetics services are generally sought as part of preconception care, prenatal care and health surveillance during childhood and adult life. Once awareness of genetic risk is identified, referral to a specialist clinical genetics service is indicated. This service is then responsible for ensuring that clinical and laboratory data are assembled at the appropriate time for making accurate genetic diagnosis, and carrying out pedigree analyses and risk estimations. This information guides genetic counselling by providing knowledge of the disorder and its significance to the individual and their family, providing preventive and therapeutic options and providing mechanisms to adjust to knowledge of the disorder and its consequences. At present the key outcomes of clinical genetics service are psychological. However, some preliminary evidence does suggest that provision of specialised clinical genetics service may contribute to a reduction in the morbidity and mortality from the complications of some genetic diseases.

The information gathered by a clinic genetics service allows for the compilation of a family-based genetic record and thereby assists with the duty of care of the clinical genetics service, which is to reach out to extended family, if the family consents.

Referral process

The referral of patients to clinical genetics services is usually initiated by a general practitioner or from antenatal or other specialist (for example, breast cancer) clinics.

In Queensland, patients requiring genetic tests and/or clinical genetics services are referred by medical practitioners for a range of tests directly to the Queensland Health Pathology and Scientific Services (QHPSS) laboratories. QHPPS laboratories are located around the state. For a small number of tests (approximately ten per cent) the referral for a test needs to be made to the clinical genetics service.

In areas such as breast cancer and colon cancer, the clinical genetics service provides a consultancy service to the specialist in charge of the patient.

There are 54 genetic and malignancy tests available in Queensland. In Europe there are approximately 500 tests available and approximately 800 available in the United States of America. If a patient in Queensland requires a test which is unavailable in the state, the clinical genetics service refers the matter to the district manager of the patient's district of residence who decides whether the health service district will pay for the tests performed interstate or overseas. In the absence of any guidelines, access to genetic testing is likely to be inconsistent and may sometimes be determined on the basis of financial criteria rather than clinical need.

Current services

In Queensland, there is one state-wide clinical genetics service. This is located at the Royal Brisbane Hospital. The Queensland Clinical Genetics Service offers diagnostic services, clinical assessment and genetic counselling services and works closely with QHPSS to provide the molecular genetic tests where testing is indicated. The Queensland Clinical Genetics Service currently sees approximately 2500 families per year.

There are no dedicated clinical genetic services provided by the private sector in Queensland. However, outreach clinics within private facilities are conducted by the Queensland Clinical Genetics Services.

Current activity

Table 1.1 describes the occasions of service provided by the Queensland Clinical Genetics Service, by zone of residence for 1998/99 to 1999/00.

Table 1.1 **Occasions of service provided by the Queensland Clinical Genetics Service by zone of residence for 1998/99 and 1999/00**

Location	1998/99 Activity	1999/00 Activity
Northern Zone		
Cairns	123	168
Townsville	432	358
Mackay	50	29
Mt Isa	18	2
Total	**623**	**557**
Central Zone		
Rockhampton	25	30
Bundaberg	47	46
Nambour	33	52
Brisbane Metro North (i)	795	864
Total	**897**	**992**
Southern Zone		
Brisbane Metro South (ii)	535	572
Toowoomba	133	133
Gold Coast	175	198
Total	**843**	**903**
Other	13	18
QLD TOTAL	**2376**	**2470**

Source: Queensland Clinical Genetics Service, 2000

Note: (i) Brisbane Metro North includes clinics conducted at the Royal Brisbane Hospitals; The Prince Charles Hospital and Redcliffe Hospital and Wesley Hospital.
(ii) Brisbane Metro South includes clinics conducted at the Mater Hospitals; the Princess Alexandra Hospital; the QEII Hospital, Ipswich Hospital; Logan Hospital and SunnyBank Private Hospital.

The QHPSS at the Royal Brisbane Hospital provide the majority of laboratory services. Small numbers of tests are also provided by the Mater Hospital laboratories and two private laboratories; Sullivan, Nicolaides Pathology and Queensland Medical Laboratory.

Contemporary practice

In the frameworks for other jurisdictions, one of the key principles stated is the need for central coordination of clinical genetic services. This avoids duplication of services, sets and monitors policy guidelines for service delivery and quality assurance standards, applies criteria for introducing new genetic tests and prioritises community needs (The Human Genetics Society of Australia, 1999).

Relevant guidelines

There are a number of relevant guidelines pertaining to the planning and provision of clinical genetics services. The World Health Organisation (WHO,1992) recommended one person with professional training in clinical genetics per 200,000 population. Comparatively, the Canadian genetics services have a ratio of one geneticist per 300,000 population (cited in NSW Health, 1993). The Canadian guidelines are consistent with those of the Human Genetics Society of Australia's, Genetic Services Subcommittee (1999) which recommend one geneticist and counsellor with one support staff per 300,000 population.

Projections

The demand for clinical genetic services is growing, particularly as a result of extension of services to cancer patients. Knowledge developed as a result of the human genome project is expected to accelerate this increase in demand.

Broad directions for service development

- That the current state-wide service model of providing clinical genetic services in Queensland, which is consistent with contemporary practice, continue.
- That all clinical genetic services be clinically linked with the state-wide clinical genetics service in Brisbane.
- That an expert group be established to determine referral criteria to ensure appropriate and equitable access to all Queenslanders.

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CHAPTER 2: SOLID ORGAN TRANSPLANT SERVICES

2.1 Renal Transplant Services

Background

End stage renal failure is defined by a greater than 90 per cent loss of renal function and is an incurable condition. The most common causes of renal failure are glomerulonephritis, diabetic nephropathy, hypertension, polycystic kidney disease and analgesic nephropathy (ANZDATA, 2000).

Renal transplantation is the optimal treatment for the majority of patients in end-stage renal failure. It improves their quality of life and may also increase long-term survival. Renal transplantation is also the most cost effective form of treatment for patients in end-stage renal failure (TRA, 2000).

Currently, the supply of donor organs is greatly surpassed by demand. A steady decline in the cadaveric organ donation rates combined with an increasing number of patients on dialysis has contributed to this trend. This declining cadaveric organ donation rate has to some extent been alleviated by slightly increasing live donor transplantations (ANZDATA, 2000). Overall however, as with national and international trends, the renal transplantation rate for Queensland is far below what is needed.

Patients with end stage renal failure who are unable to undergo transplantation have the option of disease maintenance with dialysis. This treatment is associated with a poorer quality of life, greater morbidity and significantly higher mortality as well as expense when compared to transplantation (TRA, 2000).

On average, successful kidney grafts can be expected to last approximately 15 years (AZDATA, 1999). As a result, fitter patients who have a better prognosis are more likely to be considered for transplants than patients with serious co-morbidities. In Queensland there are strict criteria for patient selection into the transplantation program.

Referral process

Patients access renal transplant services by referral from a specialist medical practitioner (a nephrologist). The patient is then assessed against set criteria for acceptance or rejection from the program. In Queensland, nephrologists refer patients with end stage renal failure from other hospitals to the renal transplant team at the Princess Alexandra Hospital (PAH). The referral is initially reviewed by a transplant surgeon, nephrologist or the recipient coordinator. The referral is then tabled and discussed at a transplant meeting which comprises surgeons and nephrologists who are involved with renal transplantation, recipient coordinator, nurse practice coordinator and social worker. The patient is triaged at this meeting based on the selection criteria. There are three possible outcomes:

- the patient meets all the criteria and is placed on the waiting list for a renal transplant
- the patient meets the majority of the criteria but further information is needed for a final decision to be made. The transplant team may request further information from the referring clinician and/or undertake additional investigations. On occasions direct review of the patient by one of the transplant clinicians may be required
- the patient does not meet the criteria and is not accepted into the program nor placed on the waiting list. The referring nephrologist can re-refer the patient if the patient condition changes.

With the current stringent guidelines for inclusion on the waiting list and the existing levels of available organs, a patient can wait, on average, from three to four years for a renal transplant. In approximately 5-10 percent of the cases, sensitised patients (patients with pre-formed antibodies who have difficulty obtaining suitable match), the wait can be much longer (Nicol ,2000).

Current services

Renal transplantation services in Queensland are only provided in the public sector. In Queensland, the Princess Alexandra Hospital (PAH) is the major provider of adult renal transplantation services and the Mater Children's Hospital (MCH) is the sole provider for paediatric renal transplantation services. The transplantations at the MCH are performed by the clinical team from the PAH.

Current activity

During 1995/96 to 1999/00 an average of 84 renal transplants per annum were performed in Queensland. The majority of transplantations occurred at the PAH with a small number of paediatric transplantations at the MCH.

Table 2.1.2 shows the number of renal transplants performed by zone, for the same five year period.

Table 2.1.2 **Number of renal transplants performed by zone of usual residence between 1995/96 – 1999/00**

Year	Northern	Central	Southern	Interstate/ Overseas	Total
1995/96	14	24	40	3	**81**
1996/97	11	21	45	3	**80**
1997/98	13	31	41	7	**92**
1998/99	19	30	35	6	**90**
1999/00	7	29	42	6	**84**
Total	52	135	203	25	**427**

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre

Contemporary practice

The patient selection criteria into the renal transplant program are developed by the PAH and informed by meetings between nephrologists and transplant surgeons. In Australia, there are no nationally endorsed guidelines covering the selection of renal transplant recipients.

Relevant guidelines

The Australian Health Minister's Advisory Council *Guidelines for renal dialysis and transplantation services* (AHMAC, 1992) are the most recent guidelines for renal transplantation service planning and provision. These guidelines state the following in terms of size and distribution of renal transplantation services:

- a minimum of 30 transplant operations per year is considered desirable, but no centre should perform less than 20 per year
- centres performing renal transplantation should be located at major hospitals with services for acute and end stage renal failure patients, to make effective use of staff and facilities
- no published optimal numbers for a transplant unit could be obtained at the time of publication however the PAH Transplant Unit considers that a second unit should be considered if transplant numbers exceed 120 transplants per annum
- the development of a stand alone second unit would also be influenced by the availability of transplantation surgeons. Four transplantation surgeons would be required for a feasible roster to ensure continuity of service. Similar numbers of nephrologists as well as appropriate dedicated junior medical staff would be required (Nova Scotia Department of Health, 2001).

The AHMAC guidelines (1992) also state that transplantation services need to be integrated with dialysis services within a renal unit or nephrology department of a major hospital as they are an integral component of a renal treatment program.

Projections

The demand for renal transplantation far exceeds the supply of transplantable organs. Table 2.1.3 provides a description of Queensland dialysis patients under the age of 65 with the likelihood of requiring a renal transplant, as at 31 March 2000.

Table 2.1.3 **Description of Queensland dialysis patients under the age of 65 with the likelihood of transplantation as at 31 March 2000**

Description	Percentages	Number
On waiting list for transplantation	31%	172
Temporary off waiting list	7%	39
Awaiting assessment	14%	77
Medically unfit, patient refusal, malignancy, age and 'other'	48%	265
Total	**100%**	**553**

Source: ANZDATA, 2000.

To eliminate the current waiting list, the number of transplants performed in Queensland would need to at least double the current rate.

A reduction in the waiting list for renal transplantation will be facilitated by strategies to increase both cadaveric organ and live donor donations. Queensland Health initiatives in this area are outlined in Section 2.4 of this paper.

Broad directions for service development

- That the Princess Alexandra Hospital remain the sole provider for adult renal transplantation services.
- That if the renal transplantation rate increases to above 120 transplants per annum, the service framework should be reviewed to determine options for a second service.
- That given the low children's renal transplant rates, a single clinical team, with an appropriate level of trained support staff (ie nursing, allied health), should provide adult and children's renal transplant services in Queensland.
- That the clinical team currently providing services at the Princess Alexandra Hospital and Mater Children's Hospital, continue to provide adult and children's renal transplant services for Queensland.

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2.2 Liver Transplant Services

Background

Adults receive liver transplantation for a number of clinical conditions including: chronic viral hepatitis, primary sclerosing cholangitis, alcoholic liver disease, primary biliary cirrhosis, fulminant hepatic failure and metabolic disorders. Overall however, as with national and international trends, the liver organ donation rate for adults, in Queensland, does not meet current need (AHMAC, 1995).

In children, biliary atresia is a key indicator for liver transplantation. The number of liver transplants for children is limited as only live donors and partial organs can be used (AHMAC, 1995).

Referral process

In Queensland, patients are referred for assessment for transplantation by a specialist medical practitioner (a gastroenterologist) to the Queensland Health, Liver Transplant Committee. The committee comprises of representatives from the Princess Alexandra, Greenslopes, Mater Children's, Mater Adult, Royal Children's and Royal Brisbane Hospitals. All patients referred to the committee are assessed and the results discussed with the patient. Patients are then either accepted onto the waiting list for the liver transplantation program or they are rejected or deferred.

For improved outcomes and management, the assessment committee prefers early referral since deferral of placement on the waiting list is preferred over late referral where organ availability and the extent of liver impairment may adversely impact on health outcomes.

Current services

There are liver transplant centres in each of the major capitals of Australia. However Brisbane, Sydney and Melbourne are the only centres that perform liver transplantation in children.

In Queensland, all liver transplants are undertaken at the Princess Alexandra Hospital (PAH) and the Royal Children's Hospital (RCH). Liver transplantation is not performed in the private sector.

Patients are accepted for transplantation from overseas, however this is decreasing as surgeons from South-East Asia have been trained and have now commenced locally based programs. It is anticipated that as the demand for services increases in Queensland, transplant services are less likely to be offered to overseas patients.

Current activity

The number of liver transplants performed in Queensland Health public hospitals from 1995/96 to 1999/00 is presented in Table 2.2.1. For adults and children, the numbers of transplants have remained relatively constant, with small fluctuations, over the five year period.

Table 2.2.2 shows the number of liver transplants performed by zone of usual residence between the same time period. As this table shows, transplants for overseas patients has gradually decreased over the last five years.

Table 2.2.1 Number of liver transplants performed in Queensland Health public hospitals by facility between 1995/96 to 1999/00

Facility	1995/96	1996/97	1997/98	1998/99	1999/00
Princess Alexandra Hospital	32	26	37	37	27
Royal Children's Hospital	17	13	12	10	15
Total	**49**	**39**	**49**	**47**	**42**

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Table 2.2.2 Number of liver transplants performed by zone of usual residence between 1995/96 – 1999/00

Year	Northern	Central	Southern	Interstate/ Overseas	Total
1995/96	5	13	3	28	49
1996/97	0	12	6	21	39
1997/98	0	7	21	21	49
1998/99	2	10	17	18	47
1999/00	5	14	13	10	42
Total	12	56	60	98	226

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Contemporary practice

To ensure consistent practice, a sub-group of the Transplant Society of Australia and New Zealand (TSANZ) meet regularly to look at protocols, consistent practices and compare outcomes.

Transplant recipients who live remote from the transplant unit need to have good communication between their local doctor and the Transplant Unit. As a major initiative to improve communication, the Liver Transplantation Unit at the Princess Alexandra Hospital is developing a web based information system, Organ Transplant Tracking Record (OTTR), to link general practitioners and local providers to the Transplant Unit.

Relevant guidelines

The Australian Health Minister's Advisory Council *Superspecialty service guidelines for liver transplantation services* (AHMAC, 1995) are the most recent guidelines for liver transplantation service planning and provision. These guidelines recommend that:

- a liver transplant unit should not be established unless an annual caseload of 20 or more is expected
- a second liver transplantation unit should not be established unless it can be demonstrated that the first unit has a high caseload (in the order of 60 annually) and does not have capacity to perform all transplantations for the state.

Projections

The demand for liver transplantation services is dependent on the incidence of end-stage liver disease and on the number of patients considered eligible for transplantation.

If patient selection criteria widen, the demand for transplantation services will increase.

In addition, the number of patients infected with hepatitis C is considered a key indicator for increased need for liver transplantation services. It has been estimated that one in every 100-200 people in Australia carry the hepatitis C virus and in Queensland, there is an average of over 2950 cases reported each year (Queensland Health, 2001). Between 50 per cent to 80 per cent of newly infected patients progress to develop chronic infection. Cirrhosis develops in about 10 per cent to 20 per cent of persons with chronic infection and liver cancer develops in one to five per cent of persons with chronic infection over a period of 20 to 30 years (WHO, 2000). Patients with liver impairment related to hepatitis C currently make up about 50 per cent of the waiting list. Within the next ten years, it is projected that these patients will make up about 95 per cent of the waiting list.

Other likely influences of future demand for liver transplantation services include projected increases in the rates of alcoholic cirrohosis patients and patients aged between 60 to 65 years with end-stage liver disease (AHMAC,1995:10).

Overall, it is expected that the number of people with end-state liver disease will increase in the future with a corresponding increase in demand for liver transplantation services. The discrepancy between the paucity of organs and the increasing numbers of potential recipients will also continue to worsen unless organ donations increase substantially or there are extraordinary breakthroughs in providing alternatives to human solid organ livers (Rosen, 1996).

Broad directions for service development

- That the Princess Alexandra Hospital and the Royal Children's Hospital continue to be the sole providers of liver transplantation services for Queensland.
- That if the liver transplantation rate increases to above 60 transplants per annum, the service framework should be reviewed to determine options for a second service.

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2.3 Heart and Lung Transplant Services

Background

Ideally, heart transplantation is performed at the latest stage of chronic heart disease which is still compatible with an optimal chance of survival (AHMAC, 1996).

Lung transplantation is indicated for patients with chronic lung disease for whom no other medical or surgical option is available and survival is limited to 12-24 months. The demand for lung transplants has remained high with patients suffering from chronic obstructive pulmonary disease, cystic fibrosis and other rare pulmonary diseases making up the waiting list. Enhanced treatment options have not had the same impact as with heart disease and low levels of organ donation continue to be an issue. There are three commonly performed lung transplantation procedures:

- combined heart-lung transplantation (HLT)
- single lung transplantation (SLT)
- bilateral sequential single lung transplantation (BSSLT).

HLT is performed where heart damage has occurred secondary to pulmonary damage, on occasions where there is disease of both heart and lungs or finally for certain types of congenital heart disease where there may be lung damage.

SLT may be performed for certain lung conditions where there is no pulmonary infection.

BSSLT is performed where there is lung sepsis, for example cystic fibrosis or bronchiectasis and in certain cases of other non-suppurative lung conditions.

Heart or lung transplant aims to improve quality of life and life expectancy and is only recommended where both of these are severely impaired.

Referral process

Heart

Referrals are made by cardiologists in both the public and private sector to the heart transplantation service at The Prince Charles Hospital. This service accepts referrals from across the state and also from northern New South Wales south to Lismore.

Approximately 150 referrals are received each year, and patients are offered a heart failure treatment service. Decisions for heart transplantation are made by the Heart Transplantation Team against international guidelines. The service will continue to manage many of these patients whilst others will return to their referring doctors with recommendations for new management regimes. Some patients will be offered transplantation as the best option. A patient referred for heart transplantation might have some preliminary investigations on an outpatient basis before being admitted to hospital for a full assessment taking a few days. Patients whose names are placed on the waiting list attend regular pre-transplantation clinics to monitor their clinical status. Some may remain in hospital due to complications of their heart disease or may require a high level of outpatient care.

Qualitative information from the QHLTU indicates that the profile of patients being accepted for transplantation has changed. The age of patients is lower, and the nature of their heart disease/illness is more acute, following a catastrophic event. Previous transplantation patients had been more chronically ill. In Queensland small children can receive transplantations, however babies are referred to Royal Children's Hospital in Melbourne. The upper age limit for heart transplantation in Queensland is notionally 60 years of age, however there is some flexibility depending on current waiting list, individual needs and availability of donated organs. The youngest recipient to date has been 8 years of age.

Lung

Referrals are made by respiratory physicians in both the public and private sector to the lung transplantation service at The Prince Charles Hospital. The service accepts referrals from across the state and also from northern New South Wales south to Lismore.

Approximately 90-100 referrals are received each year. Currently treatment options for patients are limited, although lung reduction surgery for patients with emphysema is available and some Queensland patients suffering from pulmonary hypertension have been included in clinical trials of new medication in New South Wales. Decisions for lung transplantation are made by the Lung Transplantation Team against international guidelines, and the names of patients accepted are placed on the waiting list. The indicators for transplantation include age, clinical status and psychosocial status. Patients referred for transplantation assessment and considered unsuitable are then returned to their referring physician for on-going management.

Current services

The Queensland Heart and Lung Transplant Unit (QHLTU) at The Prince Charles Hospital is comprised of the two separate service areas; heart transplantation and lung transplantation. Heart transplantations commenced in Queensland in 1990 and the first lung transplantation in Queensland was performed in 1996. The two transplantation units share facilities as the similarities between procedures and experience in one team provide a valuable resource for the other team. Appropriate cross-border arrangements exist for organ retrieval within Australia and New Zealand.

Current activity

Heart transplantations

In recent years there has been a fall in the heart transplantation rate in Queensland, which is consistent with trends internationally (Hosenpud et al, 2000). Although initially driven by the reduction in donors, advice from The Queensland Heart and Lung Transplant Unit (QHLTU) at The Prince Charles Hospital indicates that this can now be attributed also to better clinical management and improved and enhanced treatment options for patients with heart failure.

Table 2.3.1 shows that a total of 95 heart transplantations were performed between 1995 to 2000. Table 2.3.2 indicates that the majority of heart transplantation patients were aged between 45-64 years.

Table 2.3.1 Number of heart transplantations performed in Queensland between 1995 – 2000 by sex

Year	Males	Females	Total
1995	16	4	20
1996	19	5	24
1997	20	1	21
1998	9	1	10
1999	11	0	11
2000	7	2	9
Total	**82**	**13**	**95**

Source: The Prince Charles Hospital, Queensland Heart and Lung Transplant Unit

Table 2.3.2 Number of heart transplantations performed in Queensland between 1995 – 2000 by age

Year	<10 years	10 – 24 years	25 – 44 years	45 – 64 years	65 years & over	Total
1995	1	1	6	11	1	20
1996	-	2	4	18	0	24
1997	-	1	5	14	1	21
1998	-	1	5	4	-	10
1999	-	1	1	9	-	11
2000	-	4	1	4	-	9
Total	**1**	**10**	**22**	**60**	**2**	**95**

Source: The Prince Charles Hospital, Queensland Heart and Lung Transplant Unit.

Lung transplantations

Table 2.3.3 shows that 48 lung transplantations have been performed since 1996. Approximately equal numbers of lung transplantations are performed between men and women. Table 2.3.4 shows that the majority of lung transplantations patients were aged between 45-64 years.

Table 2.3.3 Number of lung transplantations performed in Queensland between 1996 – 2000 by sex

Year	Males	Females	Total
1996	2	1	3
1997	5	6	11
1998	5	8	13
1999	3	6	9
2000	6	6	12
Total	21	27	48

Source: The Prince Charles Hospital, Queensland Heart and Lung Transplant Unit

Table 2.3.4 Number of lung transplantations performed in Queensland by age

Year	10 – 24 years	25 – 44 years	45 – 64 years	Total
1996	-	-	3	3
1997	1	2	8	11
1998	2	1	10	13
1999	1	3	5	9
2000	1	2	9	12
Total	5	8	35	48

Source: The Prince Charles Hospital, Queensland Heart and Lung Transplant Unit

Heart + Lung

Only one heart + lung transplantation was performed in Queensland in 2000.

Contemporary practice

Australia has heart transplantation units in four capital cities and lung transplantation units in three. Together with a unit in New Zealand, collaborative networks and joint research are fostered by all clinicians through regularly meetings. Issues relating to heart and lung transplantation are included in the functions of the Transplantation Society of Australia and New Zealand (TSANZ).

The long-term commitment to the care of all patients undergoing transplantation services in collaboration with referring or primary physicians is internationally recognised as best practice (Stanford University Medical Centre, 2001). It is an accepted view that current service units will continue to be leaders in the management of the severe end of both cardiac disease and lung/pulmonary vascular disease developing into 'end-stage heart or lung disease management centres' rather than purely transplantation units.

Relevant guidelines

The Australian Health Minister's Advisory Council *Superspeciality service guidelines for adult heart transplantation services* (AHMAC, 1996) and *Superspeciality service guidelines for lung transplantation services* (AHMAC, 1998) are the most recent guidelines for lung and heart transplantation service planning and provision. These guidelines recommend that:

- if good long-term outcomes are to be achieved, transplantation units (heart and lung) should have an annual caseload of at least 10. (AHMAC, 1996; AHMAC, 1998)

Heart

- a second heart transplantation unit should not be established unless it can be clearly demonstrated that the first unit has a very high caseload (in the order of 60 annually) (AHMAC, 1996)

Lung

- further lung transplantation units should not be established unless the proposed unit expects an annual caseload of 20 or more (AHMAC, 1998).

Projections

Heart

Mechanical hearts, while not currently available in Queensland have been provided to some patients in Australia. These devices are large and provide only short-term support for patients, who remain in intensive care receiving mechanical ventilation. Recent advances in the technology of mechanical devices to replace the heart are being trialed in the United Kingdom. These new devices are considerably smaller, and are likely to have an impact in the next five to 10 years, which may further reduce the need for organ donation and transplantation.

Lung

The shortage of donor organs has led to interest in alternatives to whole lung transplantation. Although some of these advances are available in Australia, the impact of these technologies on the management of severe lung and pulmonary vascular disease and on lung transplantation has yet to be seen.

Broad directions for service development

- That the Queensland Heart and Lung Transplant Unit (QHLTU) at The Prince Charles Hospital continue to provide heart, lung and heart + lung transplantation services through the two service units.
- That these service units continue to be recognised as leaders in the management of severe end cardiac disease and lung/pulmonary vascular disease, developing into 'end-stage heart or lung disease management centres' rather than purely transplantation units.
- That babies requiring transplantation services (heart, lung) continue to be referred to the Royal Children's Hospital in Melbourne.

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2.4 Organ Donation

The organ donation rate (cadaver and living) for solid organs in Queensland has not increased at the required rate to meet the demand for transplantation. Table 2.4.1 shows the organ donation numbers and donors per million population from 1995 to 2000. Table 2.4.2 shows the waiting list for all Australian states for solid organs as at 1 January 2001.

Table 2.4.1 Number of donors 1995--2000 in Queensland

Year	No. of donors	Donors per mil pop
1995	34	10
1996	35	10
1997	37	11
1998	40	12
1999	20	6
2000	37	10

Source: Australia and New Zealand Organ Donation Registry, 2000

Table 2.4.2 Australian waiting list for organs at 1 January 2001

	QLD	NSW/ACT	VIC/TAS	SA/NT	WA	TOTAL
Kidney	132	757	376	111	111	1,487
Liver	14	33	22	3	1	73
Heart	2	21	27	3	5	58
Lung	21	18	49	8	0	96

Source: Data provided by the National Organ Matching Service (NOMS)

Reasons for insufficient donation rates

The organ donation rate has not been sufficient to meet increasing demand primarily because of slightly decreasing cadaver donations (ANZDATA, 2000). There are a number of reasons proposed for the decline of cadaver donor rates. Improvements in standards of health, advances in medical therapies, and legislation on driving, health and safety at work have all been successful in saving lives. Other major reasons which add to the shortfall are the lack of identification of potential donors and refusal rates. (Wight et al, 2000).

Table 2.4.3 shows the result of an audit of 10 Queensland hospitals undertaken by the Queenslanders Donate program. The result shows that in 1999, a request for organ donation was made to 39 families from a possible pool of 59 families. It also shows that less than half the families consented to organ donation.

Table 2.4.3 **Audit results of 10 Queensland hospitals 1999**

	Brain dead	Donation discussed with family	Agreement to donate	Actual donation
Number in audited hospitals	59	39	18	16
Number in 4 non audited hospitals	N/a	N/a	N/a	4
Total				**20**

Source: Queenslanders Donate

Queensland Health initiatives for increasing organ donation

In 1998/99, Queensland Health received new initiative funding to develop and implement strategies to increase organ and tissue donation in Queensland. A key strategy was the establishment of the Queenslanders Donate program, based at the Princess Alexandra Hospital. Queensland Donate aims to provide a structured and consistent approach to organ and tissue donation, and to ensure that the key elements of Australians Donate (the National Program established by the Australian Health Ministers Advisory Council) are met in Queensland.

Queenslanders Donate works with participating health services to maximise organ/tissue donation and establish a single point of contact for donation and transplantation issues. Services are provided at Cairns, Townsville, Rockhampton, Bundaberg, Nambour, Toowoomba, Royal Brisbane and the Gold Coast Hospitals.

The aims for Queenslanders Donate for the next ten years include:

- developing a centralised organ and tissue donation agency external to a hospital or District consistent with practice in other states
- provide adequate support for Queensland by increasing the current part time link nurse (local coordinator) positions to full time and increase the number of link nurses to include other hospitals in regional areas
- provide education and training to enhance the skills of clinicians in the request for organ donation in an effort to increase the consent rate, by identifying all potential donors and providing optimal care for their families
- increase further community education and awareness on donation of organs and tissues. Direct efforts in marketing and communications
- provide follow-up counselling and support for donor families.

Other initiatives impacting on organ donation

In November 2000, the *Australian Organ Donor Register* was launched. This Register is managed by the Health Insurance Commission. All Australians can now register their intent to donate. However, this does not mandate organ donation. The Health Insurance Commission is working on transferring data from the drivers license database to the registry database. The registry is a secure database and is only available to organ and tissue coordinators and not to medical personnel. This ensures that medical personnel providing clinical care to patients are not aware of patient intent.

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CHAPTER 3: HAEMOPHILIA SERVICES

Background

There are two types of haemophilia; haemophilia A and haemophilia B. Haemophilia A results from an abnormal or missing blood clotting factor VIII and haemophilia B results from abnormal or missing blood clotting factor IX. The clinical symptoms are similar.

There is a spectrum of disorders from mild haemophilia with bleeding only occurring after trauma or surgery to severe haemophilia with spontaneous bleeds occurring in joints, muscles or other organs. Bleeding can be frequent – up to once or twice per week. If not treated promptly, bleeding causes severe pain, and repeated haemorrhage into joints can cause osteoarthritis and joint deformities. Severe haemorrhage into vital organs, for example, the brain, can cause serious morbidity and possibly death.

In Queensland, approximately three to four babies are born with severe haemophilia every year. The prevalence of haemophilia is estimated to be around one per 10,000 population (World Federation of Haemophilia, 1997).

With appropriate treatment, involving the prevention and control of bleeding, the life expectancy of haemophiliacs is approaching that of normal people (N.S.W. Genetic Education Program, 2000; The Wessex Institute for Health Research and Development, 1997; World Federation of Haemophilia, 1997; Haemophilia Society, Bristol and South West Group, 2001).

Treatment to prevent haemorrhage (prophylaxis), is administered as an intravenous injection using either recombinant or blood products, and can be administered at home by the person with haemophilia or a parent/carer. Prophylactic therapy is routinely administered to children with haempophilia as they do not have existing joint damage. Prophylactic therapy is continued into adulthood at which time it is reviewed. Adults may choose not to have prophylactic therapy and instead have therapy when needed as a result of a bleed. However, prophylactic therapy is administered to adults prior to surgery (The Wessex Institute for Health Research and Development, 1997; The Haemophilia Society, 2000).

Previously, plasma derived products transmitted HIV and Hepatitis and have the potential to transmit other human pathogens. Recombinant factor VIII or IX is the preferred treatment product. Recombinant factor VIII is manufactured using tissue culture, thereby avoiding the use of plasma. Recombinant products are however expensive.

Emerging technology

Haemophilia is an appropriate target for gene therapy as complete correction of the defect is not required to prevent major morbidity of the disease. Gene therapy may provide an alternative to repeated injections by using several genetically modified vectors to express the corrected gene to manufacture the required protein. Gene therapy for haemophilia B are currently in Phase I and II trials (Kaleko, 2000).

Referral process

Patients are referred to the Haemophilia Centre at either the Royal Brisbane Hospital or the Royal Children's Hospital by general practitioners, or are self referred. There is a network of haemophilia centres throughout Australia and overseas. Arrangements are made for people on holidays or relocating to access a haemophilia centre.

Current services

In 1999, Queensland Health established a coordinated Haemophilia Centre at the Royal Brisbane Hospital Health Service District and the Royal Children's Hospital Health Service District that provides services for both adults and children, respectively. The Haemophilia Centre provides the following functions:

- a single point accountability for the care of patients with bleeding disorders with responsibility for the coordination, allocation and distribution of therapeutic resources
- a clinical service by experienced staff for persons with bleeding disorders and their families at short notice
- organisation of home therapy programs
- counselling and advisory service for people with haemophilia and their families including genetic counselling and family planning
- specialist medical expertise, principally haematology, surgery, infectious diseases and dental services
- specialist allied health services
- a laboratory service able to carry out all investigations required for the accurate diagnosis of haemophilia and other inherited disorders of haemostasis and to have access to specialised testing facilities such as gene typing
- a system to record all investigations, treatments, allocation of therapeutic products and adverse reactions
- a capability to participate in research including clinical trials
- educational programs for medical staff, other personnel, patients and their families
- an outreach program to isolated patients and treating medical services.

The Haemophilia Centre conducts outreach clinics at Gold Coast, Toowoomba, Townsville and Cairns with plans to provide an outreach service at Nambour in the near future. Most new patients are admitted initially for assessment and for inserting a venous access line. Patients or family members are generally able to self-administer the intravenous therapy.

Patients are provided with a prescription for recombinant products by the Haemophilia Centre that can be dispensed by selected hospital pharmacies. Plasma derived products are available from local hospitals. The products usage is monitored by the Haemophilia Centre. Currently, recombinant products are provided to approximately 35 per cent of patients under appropriate guidelines and 65 per cent of patients receive plasma products.

Patients are followed up at least every six months either at the Haemophilia Centre or by the centre staff in an outreach setting.

Current activity

There are approximately 110 patients with severe haemophilia in Queensland. The number of haemophilia separations and number of haemophilia patients under 14, and over 14, in 1999/00 are shown in Table 4.1 and Table 4.2 respectively.

Table 4.1 **Number of haemophilia separations and number of haemophilia patients under 14 in 1999/00**

Hospital	Number of patients	Number of separations
Boonah Hospital	1	2
Caboolture Hospital	1	1
Cairns Base Hospital	1	1
Cunnamulla Hospital	1	1
Esk Hospital	1	1
Gold Coast Hospital	1	7
Gympie Hospital	1	2
Mareeba Hospital	1	1
Mater Children's Hospital	12	52
Nambour General Hospital	1	3
Redcliffe Hospital	1	151
Rockhampton Hospital	1	1
Royal Children's Hospital	18	72
Wujal Wujal Community Hospital	1	1
Total	42	295

Note: The number of haemophilia patients is based on patient identifiers which are not unique state-wide. Therefore an individual patient may be counted at a number of hospitals within a time period.

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Table 4.2: **Number of haemophilia separations and number of haemophilia patient over 14 years in 1999/00**

Hospital	Number of patients	Number of separations
Gold Coast Hospital	4	5
Royal Brisbane Hospital	22	71
Other	**6**	**14**
Total	**32**	**89**

Note: The number of haemophilia patients is based on patient identifiers which are not unique state-wide Therefore an individual patient may be counted at a number of hospitals within a time period.

Six hospitals had a single patient during 1999/00 with a total of 14 separations. These facilities were Cairns Base, Collinsville, Goondiwindi, Nambour General Redland and the Royal Children's Hospitals

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Contemporary practice

Centre based care with a specialised team of staff provides the most effective and efficient service to haemophilia patients (Evatt, 2000; United Kingdom Haemophilia Centre Directors Organisation Executive Committee, 1997).

As recombinant clotting factor concentrates are much safer than plasma-derived products with respect to viral transmission, there is a movement away from plasma derived products towards recombinant products (The Wessex Institute for Health Research and Development, 1997; MASAC Recommendation #106).

Relevant guidelines

In 1993, the NHS Management Executive, produced the *Provision of haemophilia treatment and care* to guide purchasing in the UK, and provide information on services to be provided by comprehensive haemophilia care centres.

The United Kingdom Haemophilia Centre Directors Organisation Executive Committee have produced a series of relevant guidelines including the *Blood Coagulation and Fibrinolysis guidelines* (1996) and the *Guidelines on therapeutic products to treat Haemophilia and other hereditary coagulation disorders* (1997).

The United States National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC) is composed of scientists, physicians, and other treatment professionals and are experts in the fields of blood safety, bleeding disorders, AIDS, hepatitis and other infectious diseases. MASAC promulgates medical information and recommendations relevant to the bleeding disorders community. For example, MASAC Recommendation #106 is *MASAC Recommendation Regarding the Use of Recombinant Clotting Factor Replacement Therapies*.

Projections

There are predictions for an increasing number of men (from 10 to 80 per cent) with haemophilia reaching reproductive fitness as they survive longer. This is predicted to cause an increase in boys born with severe haemophilia in families with a family history. This increase in survival is likely, over time, to increase the population of people with haemophilia requiring treatment (Kasper, 2000).

With improvements in technology and diagnostic tools, it is anticipated that there will be an increase in the diagnosis of milder cases of haemophilia and in bleeding disorders in women (Lusher, 2000). With the availability of prophylactic treatment, the option of pregnancy termination after antenatal diagnosis is expected to continue to decrease. The impact of gene technology on the numbers of haemophiliac cases is difficult to determine and will need to be monitored.

Broad directions for service development

- That the current model of a state wide haemophilia centre with outreach services continue.
- That there be movement towards full availability of recombinant products from the existing combination of approximately 35 per cent recombinant products and 65 per cent plasma derived products.

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Section 2 : Whole of State Services, Complex End of Service Continuum

CHAPTER 4: BURNS SERVICES

Background

A burns unit is a special type of patient care unit specifically designed, staffed and equipped for the care of the severely burnt patient. It may provide various levels of care, but is essentially designed for the requirements of the acutely ill, severely injured patient.

Contemporary burns care for the severely burnt patient has become highly specialised involving prompt attention to respiratory support, fluid restoration, wound care and excision, nutritional supplementation, adequate pain management, intensive physical therapy, pro-active scar management, and emotional and psychological support (Nguyen et al, 1996; Barillo et al, 1999).

The Queensland Injury Surveillance Unit data for a six month period from January to June 1998 indicates that there were 511 cases of burns and scalds during this period. The breakdown of these cases was as follows:

- nearly 30 per cent of the burns involved children under five years of age
- 40 per cent involved exposure to hot liquids, steam or gas
- two thirds happened in the home
- nearly 30 per cent involved hot food
- 15 per cent involved heating and cooking appliances
- 40 per cent involved upper limbs
- more than 40 per cent involved multiple sites
- 15 per cent were admitted to hospital (cited in QH, HSSB, 2000:29).

Emerging technology

One area of technological change is in the substances used to protect the burn area before a graft can be applied. There is a growing range of bio-engineered temporary skin substitutes available for this purpose (Morgan, 1997). Some of these products have been used by the states major referral centres for burns care with varying degrees of success. The products that have been used are high cost.

For skin grafting, autologous tissue is preferred and there have been rapid advances in local capacity to produce autologous tissue through the Australian Red Cross in Brisbane. Cadaver skin is the gold standard for temporary wound closure and can be used instead of the more expensive bioengineered skin equivalents (Carsin, 2000).

While there is emerging technology in the form of bio-engineered temporary burns coverage products, the main gains in terms of survival and healing times have already been achieved in respect of growing autologous tissue for grafting on burns patients (Carsin, 2000).

Referral process

Patients presenting to emergency departments of Queensland Health hospitals who meet criteria consistent with the Australia and New Zealand Burns Association guidelines (ANZBA, 2001) are referred to a major referral centre for burns.

Current services

Currently, the Royal Brisbane (RBH) and the Royal Children's (RCH) hospitals are the major referral centre for burns for the state.

The services at these hospitals comprise an in-patient component, an outpatients service, day admissions service and follow-up support. As well, they provide a 24 hours consultation service to the rest of the state. Both the RBH and RCH have support services to manage the severely burned patient. These include intensive care services and operating theatre support.

Once the acute admission concludes, patients requiring further grafting and support are managed as day cases or through the provision of other ambulatory services. Following a severe burn, patients are reviewed every two to three weeks for up to two years.

Less severe burns can be treated in other Queensland hospital facilities. However, if any specialist problems occur or are anticipated, they are usually referred to either the RBH or RCH (Pegg, 2000).

Current activity

Table 5.1 shows the number of separations for children and adults involving burns to more than 10 per cent and 20 per cent of the total body surface area, respectively, for 1999/00 at Queensland public hospitals.

The number of separations in children under 15 years of age is more than double that for adults. While a small number of severely burnt patients are treated in hospital facilities around the state, the RCH and the RBH accounted for the greatest number of patient separations.

Table 5.1 **Number of separations for children (under 15 years of age) for burns involving more than ten per cent of the total body surface area (TBSA) and number of separations for adults (over 14 years of age) involving burns to more than 20 per cent of the TBSA for 1999/00 at Queensland public hospitals (i) (ii)**

Hospital	Children	Adults
Royal Children's Hospital	104	-
Royal Brisbane Hospital	1	52
Blackwater Hospital	8	-
Townsville General Hospital	7	1
Princess Alexandra Hospital	1	5
Cairns Base Hospital	3	2
Mater Misericordiae Children's Hospital	4	-
Gladstone Hospital	1	3
Ipswich Hospital	3	-
Gympie Hospital	1	2
Mount Isa Base Hospital	3	-
Wynnum Hospital	-	2
Other (iii)	20	6
Total	**153**	**73**

Note: (i) All transfer patients are excluded.
(ii) This table is provided as indicative data only.
(iii) The hospitals clumped in this category had 1 or 0 separations. The total number of hospitals in this category was 21 and these hospitals are: Rockhampton, Toowoomba, Thursday Island, Mareeba, Collinsville, Redcliffe, Gold Coast, Ayr, Bowen, Bundaberg, Nambour, Mackay, Boonah, Hervey Bay, Julia Creek, Roma, Beaudesert, Mungindi, Logan, Maryborough and Mornington Island Hospital.

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Contemporary practice

Evidence suggests that optimal outcomes, including reduced mortality rates and improved quality of life, for the severely burnt patient are achieved through complex care delivered by skilled, multi-disciplinary teams using modern technology in units dedicated to burn care (ASCHMC, 1982; Waitzman and Neligan, 1993; Nguyen et al, 1996; Barillo et al, 1999; Toouli et al, 2000). Studies also suggest that management of severe burns in a burns unit is more cost efficient than in an intensive care unit (ASCHMC, 1982; Toouli et al, 2000).

Given that the care of Queensland patients with severe burns is concentrated in two major referral centres located in Brisbane, development of outreach services to non-metropolitan areas through use of tele-medicine is indicated. Although centralized care in a burns units is considered best practice for the care of the severely burnt patient (ASCHMC, 1982; Waitzman and Neligan, 1993; Nguyen et al, 1996; Barillo et al, 1999; Toouli et al, 2000), extending expertise across the state through use of tele-medicine will provide support to clinicians providing burns care in rural and remote areas of the state and assist their patients who might otherwise be required to travel long distances for burns care.

Relevant guidelines

Queensland public hospitals use criteria consistent with the Australian and New Zealand Burn Association guidelines to refer patients with severe burns to a major referral centre for burns in the state (ANZBA, 2001). These guidelines recommend that patients with any of the following should be referred to a recognised burns unit:

- burns greater than 10 per cent of total body surface area
- burns of special areas – face, hands, feet, genitalia, perineum and major joints
- full-thickness burns greater than 2 per cent of total body surface area
- electrical burns
- chemical burns
- burns with an associated inhalation injury
- circumferential burns of the limbs or chest
- burns at the extremes of age – children and the elderly
- burn injury in patients with pre-existing medical disorders which could complicate management, prolong recovery or affect mortality
- any burn patient with associated trauma.

Projections

The number of patients requiring specialist burns treatment services is not anticipated to significantly increase in the future. This is despite the population increases, indicating that preventive programs may have been successful in lessening the incidence of burn injuries (Pegg, 2000).

While the units would be overwhelmed by a major catastrophy, contingency planning has been made in the Queensland Health Disaster Plan (QH, EHS 2000).

Broad directions for service development

- That the Royal Brisbane Hospital and the Royal Children's Hospital continue to be the hospitals providing a single state-wide service for treatment of patients with burns injuries.
- That outreach services, through the use of tele-medicine networks, be developed for remote patients from Brisbane.

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Section 3: Zonal Services, Stand Alone Services

CHAPTER 5: HAEMOPOIETIC STEM CELL TRANSPLANTATION SERVICES

Background

Haemopoietic stem cells are blood forming cells that grow in the bone marrow and provide a continuous supply of red blood cells, white blood cells and platelets. In cancer patients, haemopoietic stem cell transplantation is used to regenerate the patient's blood cells after very high doses of chemotherapy and radiotherapy are given. In non-cancerous conditions, haemopoietic stem cell transplantation is used to replace deficient or defective bone marrow cells (AHMAC, 1999; Johnson et al 1998).

Transplants can either be autologous (using the patient's own stem cells) or allogeneic (using stem cells taken from a related or unrelated donor).

Over the last 30 years, haemopoietic stem cell transplantation has developed as a therapy to treat a number of cancerous and non-cancerous conditions. It has become standard therapy for acute and chronic leukaemia, non-Hodgkin's and Hodgkin's lymphoma, aplastic anaemia and other less common diseases (AHMAC, 1999). Currently, it is not standard therapy for breast cancer.

The types of transplantation are:

- allogeneic transplantation where stem cells are taken from a related or unrelated donor with compatible stem cells
- autologous, where the patient's own stem cells are used for the transplant
- syngeneic, where the donor is an identical twin
- cord blood allogeneic transplantation. This is a new technology involving cord blood as a source of progenitor cells. The effectiveness of this method is still under investigation.

There are a number of stages in haemopoietic stem cell transplantation:

- harvesting stem cells from the patient or donor by a method that maximises the yield. There are two major sources of stem cells: the bone marrow where they are produced (BMT), and the peripheral blood (Peripheral Blood Progenitor Cell Transplantation)
- administering high-dose conditioning chemotherapy or radiotherapy
- infusing the harvested stem cells into the patient
- continuing care and therapy to reduce the risk of infection until the transplanted stem cells engraft.

Management of the patient after transplantation may involve management of graft versus host disease where the infused cells recognise the patient as foreign and establish a hostile immune response. This is more likely to occur with allogeneic transplantation (Harrisons On Line, 1999).

Emerging technology

There has been a major extension of clinical practice involving drug treatment before transplantation that does not eliminate the bone marrow (non-myeloablative therapy). The resulting transplant causes less toxicity and less graft versus host disease, with improved survival and reduced transplant related morality (Harrisons On Line, 1999). The effect of this new approach may impact dramatically on the provision of transplantation in Queensland. However, it should be noted that this is an experimental procedure. The data has yet to demonstrate that this technique produces a superior outcome.

Referral process

Patients with indications for haemopoietic stem cell transplantation are referred by their general practitioner, physician or haematologist to a haemopoietic stem transplant unit for investigations. Patients are diagnosed with blood tests and generally there are early referrals for haemopoietic stem transplantation if this is required.

Current services

The haemopoietic stem transplantation type available at facilities in Queensland is shown in Table 6.1.

Current activity

Between 1992 and 1997, the number of haemopoietic stem cell transplantation has almost doubled in Australia (AHMAC, 1999).

In Queensland the haemopoietic stem transplantation activity over a five year period 1995/96 to 1999/00 is provided in Table 6.2 and Table 6.3. The proportion of activity in each zone reflects the zonal population.

Table 6.1 **Haemopoietic stem transplantation type available at Queensland Health facilities**

Facilities in which transplantation is undertaken	Type of transplantation	
	Allogeneic	Autologus
Royal Brisbane Hospital	3	3
Princess Alexandra Hospital	-	3
Mater Adult Hospital	3	3
Townsville General Hospital	3	3
Royal Children's Hospital	3	3
Mater Children's Hospital	3	3
Mater Private	3	3
Wesley Hospital	3	3
Greenslopes Private Hospital	3	3
Holy Spirit	-	3
John Flynn Hospital	-	3

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Table 6.2 **Number of allogeneic and autologous haemopoietic stem transplantation in Queensland public facilities from 1995/96 to 1999/00**

Facility /Year	1995/96		1996/97		1997/98		1998/99		1999/00	
	Allo	Auto	Allo	Auto	Allo	Auto	Allo	Auto	Allo	Auto
Royal Brisbane Hospital	51	46	67	46	58	35	46	37	72	26
Princess Alexandra Hospital	-	-	-	17	-	17	-	21	-	11
Mater Adult Hospital	-	30	-	83	4	101	-	57	1	37
Townsville General Hospital	-	-	-	-	-	-	-	19	2	21
Royal Children's Hospital	4	5	5	4	2	9	8	5	6	16
Mater Children's Hospital	-	-	-	-	-	1	-	7	4	3
Total	**55**	**81**	**72**	**150**	**64**	**163**	**54**	**146**	**85**	**114**

Note: Allogeneic data is based on ICD 10 codes 13706-00 and 13706-06 for 1999/00 and compatible codes in ICD9-CM for the previous years. Autologous data is based on ICD 10 codes 13706-07 and 13706-08 for 1999/00 and compatible codes in ICD9-CM for the previous years.

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Table 6.3 Number of allogeneic and autologous haemopoietic stem transplantations performed by zone of usual residence between 1995/96 – 1999/00 for all Queensland hospitals (public & private)

Year	Northern		Central		Southern		Interstate/ Overseas	
	Allo	Auto	Allo	Auto	Allo	Auto	Allo	Auto
1995/96	7	11	22	31	22	39	4	3
1996/97	11	20	23	47	35	85	3	16
1997/98	10	17	27	63	28	119	3	18
1998/99	5	39	26	62	22	99	2	9
1999/00	8	38	40	70	55	88	10	10

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Contemporary practice

There are two sets of published guidelines relevant to contemporary practice regarding the collection, testing and storage of cells for transplantation. Firstly, there are those produced by a working group of the World Marrow Donor Association. These guidelines and recommendations relate to international bone marrow and blood stem cell transplants and include:

- guidelines for establishing the extent and quality of histo-compatibility testing for unrelated donor registries, umbilical cord blood banks and transplant centres involved in international exchange of haematopoietic stem cells for allogeneic transplantation (Hurley et al, 1999)
- recommendations for 'donor work-up' (Cleaver et al, 1997).

Secondly, there are guidelines produced by a working party of the Haemopoietic Stem Cell Processing, Haematology Discipline Advisory Committee, the Royal College of Pathologists of Australasia. These guidelines relate to the collection, processing, storage and administration of haematopoietic stem and progenitor cells for transplantation (Shepherd et al, 1999).

Relevant guidelines

The Australian Health Minister's Advisory Council *Superspeciality service guidelines for haemopoietic stem cell transplantation* (AHMAC, 1999) are the most current guidelines for haemopoietic stem cell transplantation service planning and provision. These guidelines recommend the following minimum caseloads:

- each unit carrying out autologous transplants only should aim to perform a minimum of 30 transplants per year
- each unit carrying out both allogeneic and autologous transplants should aim to perform a minimum of 50 transplants per year (at least 10 should be allogeneic transplants)

- for paediatric units the minimum caseload for allogeneic and autologous transplants should be 10 per year. The optimum number of allogeneic and autologous transplants carried out per year should be 50. Where paediatric units have access to shared facilities so that cost effectiveness is no longer a factor, the minimum caseload is 10 transplants per year.

A recent study reported in the Lancet showed that centres undertaking more than 39 allogeneic transplantations per year had significantly better leukaemia free survival than centres carrying out a smaller number of transplantations (Frassoni et al, 2000).

When comparing the AHMAC guidelines (AHMAC, 1999) with current levels of allogeneic and autologous haemopoietic stem transplantation in Queensland public facilities (Table 6.2) a number of conclusions can be drawn. Firstly, only one adult and one children's hospital meet the recommended minimum caseload considerations for allogeneic transplantation. Secondly, some of the hospitals do not meet the recommended minimum caseload for autologous transplantation.

Projections

AHMAC has predicted that demand for haemopoietic stem cell transplantation will continue to grow over the next 10 years, particularly for autologous transplants in adults and children and for cord blood transplants in children (AHMAC, 1999).

AHMAC has produced a range of projections relating to haemopoietic stem cell transplantation (AHMAC, 1999). The projected Queensland demand for haemopoietic stem cell transplantation in paediatric and adult units in 2006 are provided in Table 6.4.

Table 6.4: Projected Queensland demand for haemopoietic stem cell transplantation in paediatric and adult units in 2006

Type of transplantation	Projection A (iii)		Projection B (iv)	
	Low (i)	High (ii)	Low	High
Child Allogeneic	8	15	19	33
Child Autologous	4	7	19	30
Adult Allogeneic	62	72	62	72
Adult Autologous	125	245	162	319

Source: AHMAC 1999.

Note: (i) The 'low' projection of demand factors in demographic changes to the population and population growth only.

(ii) The 'high' projection of demand allows for demographic changes but also includes the broadening of indications for transplantation and increased availability of matched unrelated donor bone marrow.

(iii) Projection A was made by allocating projected demand for allogeneic and autologous adult transplants in Australia as a whole to the States and Territories according to their respective proportions in 1996.

(iv) Projection B was made by increasing the projected rates of allogeneic and autologous transplantation in each state to equal those in the state with the highest rate (AHMAC, 1999)

The AHMAC projections in relation to autologous caseloads in 2006 should be interpreted with caution as they were formulated at a time when there was an explosion in the use of autologous transplantation for breast cancer and it has since been found that this does not improve survival. Similarly the advent of non-myeloablative allogeneic transplantation may increase utilisation and AHMAC projected caseloads may represent an underestimate.

Broad directions for service development

- That all hospitals that meet the AHMAC caseload recommendations for haemopoietic stem cell transplantation continue to provide this service.
- That all hospitals that do not meet the caseload considerations be reviewed in terms of safety and quality of the services provided.

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CHAPTER 6: ADULT CYSTIC FIBROSIS SERVICES

Background

Cystic fibrosis (CF) is a common autosomal recessive genetic disorder. CF effects many organs in the body, especially the lungs, pancreas and sweat glands. Abnormal secretions lead to respiratory problems, incomplete digestion and increase salt loss from the sweat glands. In the lungs, the mucus which is secreted is thick and sticky, clogging the small air passages and encouraging bacterial growth. Repeated infections and blockages can cause severe lung damage. Similarly the ducts from the pancreas to the intestines can become blocked (N.S.W. Genetic Education Program, 2000).

The treatment of CF depends upon the stage of the disease and the organs affected. Treatment options include: chest physical therapy to dislodge the thick mucus from the lungs and antibiotics to treat lung infections. Antibiotics may be administered intravenously, orally, and/or as medicated vapours which are inhaled. Treatment must be continuous for palliation and to prevent further infections. Enteral supplements are provided to patients with digestive problems (Cystic Fibrosis Foundation, 2001).

Specialised care for adult patients with CF involves providing care by a specialised multi-disciplinary team (Mahadeva, 1998; Shale, 1992). The support services required for a CF centre include: gastroenterology, microbiology, infectious diseases, thoracic surgery, general surgery, lung transplant, obstetrics and gynaecology, clinical genetics and ear, nose and throat services.

Improved treatment of children with CF has resulted in extended survival into adulthood. Adults with CF continue to benefit from improvements in clinical care, broader treatment options and coordinated centre based care (Walters et al. 1994). This has resulted in better quality of life with more successful employment options. As treatment regimes expand and become increasingly complex, it is becoming more expensive to provide this care. This is particularly the case in the last years of the persons life as the quality of life declines significantly and increased medical input and overall resources are required to maintain quality of life (Konstan et al, 1999).

It is estimated that 1:2500 children are born with CF each year, with 1:25 persons in the Australian population being carriers of the faulty gene. Carriers of the cystic fibrosis gene mutation are asymptomatic, however because of the prevalence of the mutation, the incidence of the disease is relatively high (N.S.W. Genetic Education Program, 2000). It is estimated that there are approximately 450 people with cystic fibrosis in Queensland. Approximately 170 of these people are over 18 years of age.

Emerging technology

Cystic fibrosis is an appropriate target for gene therapy as complete correction of the defect is not required to prevent major morbidity of the disease. Gene therapy may provide an alternative to current therapies by using several genetically modified vectors to express the corrected gene to manufacture the required protein. Gene therapy for cystic fibrosis is currently the focus of a number of clinical studies (Cystic Fibrosis Foundation, 2001).

Referral process

The vast majority of patients with CF are diagnosed at early age by a paediatrician. There is a transition phase from paediatric care to adult care which generally occurs between age 16 to 18. The teams from both children and adult services are involved in the transition phase.

Current services

The majority of adults with cystic fibrosis are cared for by The Prince Charles Hospital (TPCH). Mater Adults Hospital (MAH) provides care for the second largest group of adult patients with CF.

The severity of the disease dictates the level of service a patient receives. The CF service at TPCH and the MAH conduct an outpatient clinic twice a week to cater for the needs of patients with CF. Patients are reviewed at intervals ranging from monthly to six monthly depending on their condition. Patients managed under share-care arrangements with another hospital are reviewed every six months at a CF centre. TPCH provides a six monthly outpatient clinic at Cairns, Townsville and Mackay.

Both TPCH and the MAH have a consistent inpatient caseload of eight to 10 patients. The average length of stay for these patients is 10 days. The average course of antibiotics takes 14 days with patients starting intravenous antibiotics in the hospital and completing the course as "hospital in the home" patient.

The MAH in partnership with TPCH is involved in research to improve clinical care for patients with CF.

Current activity

In Queensland there are approximately 170 adult patients with CF. TPCH has approximately two thirds of these patients under its care with the remaining one third cared for by the MAH. The number of hospital separations in 1999/00 for patients over 15 years of age with cystic fibrosis is provided in Table 7.1.

Table 7 1 Number of separations in 1999/00 for patients over 15 years of ages with cystic fibrosis

Hospital	No. of separations
The Prince Charles Hospital	271
Mater Adult Hospital	60
Gold Coast Hospital	38
Royal Children's Hospital	35
Rockhampton Base Hospital	24
Townsville General Hospital	14
Mater Children's Hospital	13
Cairns Base Hospital	12
Royal Brisbane Hospital	12
Toowoomba Hospital	7
Bundaberg Base Hospital	7
Mareeba District Hospital	6
Caboolture Hospital	4
Mackay Base Hospital	4
Ayr Hospital	2
Nambour General Hospital	2
Other[i]	7
Total	**518**

Note: Number of seperations identifies the number of episodes of care and does not identify number of patients.

(i) "Other" represents hospitals with 1 separation in the year and these are for the following hospitals: Beaudesert, Caloundra, Dalby, Emerald, Hervey Bay, Jandowae and Maleny Hospital.

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Contemporary practice

There is increasing evidence to suggest that specialised centre based care leads to improved outcomes (The Royal College of Physicians of London, 1990). At this time there is no benchmarking of outcomes between different centres. No state-wide information system exists to collect the information that would facilitate benchmarking.

Evidence also suggests that intensive appropriate treatment improves quality of life and removes patient dependency form institutional care (Conway et. al., 1998 and Cottrell and Burrows, 1998).

Relevant guidelines

The Royal College of Physicians of London recommended (1990) that the care of CF patients should be delivered by a specialist team in a CF centre. This view was supported by the Cystic Fibrosis Trust, British Paediatric Association and the British Thoracic Society in their recommendations on care of cystic fibrosis (1996).

While there are no published guidelines, a senior clinician in Queensland believes that a CF centre should look after a minimum of 40 patients and a maximum of 200 patients (Bell,2000).

Projections

With more effective genetic screening, it is anticipated that there will be a decrease in the incidence of CF. However, the number of patients progressing to adulthood is expected to increase due to better management (Conway et al, 1998).

Previously, children did not survive well into adulthood. Currently, adults with CF are expected to survive up to 32 years of age. People with CF born in 1990 are expected to live until age 40. By the year 2010, it is anticipated that there will be equal number of people with adult and paediatric CF (Elborn et al, 1991; Conway et al, 1998). The current services were developed with past projected survival rates in mind and therefore service development and delivery at the adult end of the spectrum requires further consideration, based on the improved survival rates.

Taking both survival rates and genetic screening into consideration, it is predicated that there will be an initial increase in the number of adults with CF, however this will decline as the pool of patients with CF decreases due to genetic screening and gene therapy. The impact of gene technology on numbers of CF cases is yet to be defined. The decline in CF numbers is unlikely to influence planning processes in the short to medium term.

Broad directions for service development

- That the coordinated development of the two state-wide specialised adult cystic fibrosis centres continue
- That staff in other facilities are systematically educated on the provision of follow-up care for patients with adult cystic fibrosis.

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CHAPTER 7: NEONATAL SERVICES

Background

Neonatal intensive care (ICN) and special care (SCN) units provide medical, nursing and allied health support for newborn babies who require specialised diagnosis and treatment.

The data below is indicative of the principle neonatal conditions commonly treated and managed within a specialist neonatal unit:

- 5.3% of babies are low birth weight i.e. <2500 g to 1500 g
- 0.9% of babies are very low birth weight i.e. <1500 g to 1000 g
- 0.6% of babies are extremely low birth weight i.e. <1000 g
- 4.2% of babies have at least one congenital anomaly
- 36% of babies required resuscitation other than routine suction
- 15.2% of babies required at least one neonatal treatment

Source: The Perinatal Statistics Report, Queensland Health, 1998

Specialised neonatal services also provide:

- antenatal consultation where neonatal illness is expected
- assessment and treatment of babies who do not require admission to neonatal units
- specialised transport services for babies requiring special or intensive care.

Neonatal units are classified according to the intensity of the care provided. The Guidelines for Clinical Services in Private Health Facilities, produced by the Office of the Chief Health Officer, Queensland Health in 2000 describes the following:

- **Level III** units / Neonatal intensive care units – provide the highest level of life support including medium-long term ventilation of babies

- **Level II** units / Special care units – provide less intensive care and may be used in a "step down" capacity. Level II Units may be divided into **Level IIa** and **IIb**, where the higher level (IIa) has the capacity for a greater level of complexity in management, including the capability for ventilation up to 48 hours. The nature of this practice is usually to stabilise the baby on ventilation, in consultation with the neonatologist at the Level III unit, prior to transfer to a Level III facility. Precise definition within these levels is not always possible as the level at which a baby is managed may vary dependent on the size and staffing of the unit

- **Level I** units – primarily care for healthy infants of greater than 36 weeks gestation but are not considered in detail in the context of this specialist services statement (CHO, QH, 2000).

Referral process

AHMAC guidelines indicate that "wherever possible, preterm birth at less than 33 weeks should occur in a perinatal centre that has the expertise to care for the woman and her preterm infant". These guidelines further recommend that clear advice and support be provided to women and their families when transfered to a perinatal centre and that every effort be made to keep the baby with or as close as possible to the mother during the post natal period (AHMAC, 2000).

The referral process in Queensland relies on consultation with neonatologists at the Level III units by medical practitioners at the hospitals managing at risk new-born infants. If higher level care is indicated, transport arrangements are made. Retrieval services from the Level III units travel to the hospital of birth. In practice neonates less than 32 weeks gestation or <1500 g are most frequently referred to a Level III neonatal facility.

The Perinatal Statistics Report (QH, 1998) indicated the following:

- antenatal transfer of 1129 mothers, representing 2.4% of mothers delivering in Queensland
    - 540 were transferred into a facility with Level III Unit
    - 518 were transferred into a facilty with Level II Unit.

Additionally, after birth:

- 325 babies were transferred into a Level III facility
- 441 babies were transferred into a Level II facility.

Current services

Current neonatal services in Queensland have a zonal focus. One Level III Unit is located in each zone with networks within each zone and to a lesser extent across zones, particularly in the South-East of the state. These networks extend to northern New South Wales and south to approximately Lismore.

Level III Services – Neonatal intensive care units are provided at three hospitals. Details of these hospitals capacity for both intensive and special care is provided in Table 8.1. These three neonatal units have a combined notional total of 60 cots for neonates requiring intensive care across the three zones and for babies transferred in from northern NSW.

Level II Services – Special care nurseries are provided (at varying levels of Level II) at 16 public and 15 private hospitals in addition to the three hospitals providing Level III services

The Prince Charles Hospital provides intensive care facilities for neonates following complex cardiac surgery.

Table 8.1: Queensland Hospitals with Level III Neonatal Facilities

Hospital	ICN cots	SCN cots	Total
Royal Women's Hospital (i)	30	36	66
Mater Misericordiae Mothers' Hospital (ii)	20	40	60
Kirwan Hospital for Women (iii)	10	24	34

Note: These figures are notional only and subject to a number of factors including the availability of human and financial resources.

Source: (i) Royal Women's Hospital Health Service District.
(ii) Mater Misericordiae Mother's Hospital This data includes public and private patients.
(iii) Townsville Health Service District

Current activity

In 1999, 48,704 babies were born in Queensland. Of this total number, 12,490 (25.6%) were managed in private hospitals. In addition, 4,800 babies were born in northern New South Wales. Table 8.2 identifies the total number of admissions to the three hospitals having Level III cots, and babies who were admitted to Level II cots within these facilities.

Table 8.2 Admissions to ICN/SCN in hospitals with Level III facilities. 1/1/99 to 31/12/99

Hospital	ICN/SCN total	Total occupied bed days
Royal Women's Hospital (i)	1100	20611
Mater Misericordiae Mothers' Hospital (i)	2544	18628
Kirwan Hospital for Women (ii)	499	5881

Note: Separate data for ICN and SCN admissions has only been collected by the Perinatal Data Collection since July 2000

Source: (i) Royal Women's Hospital Health Service District.
(ii) Mater Misericordiae Mother's Hospital. This data includes public and private patients.
(iii) Townsville Health Service District

Contemporary practice

The following practices are used in Queensland:

- that neonatal services providing Level III services are co-located with the highest level of specialist obstetric services which serves to concentrate expertise and use these high cost services efficiently

- that active clinical intervention, including resuscitation where necessary, is offered to all babies born at 24 weeks and over.

Relevant guidelines

Current guidelines which are accepted practice in Queensland include the following:

- wherever possible, babies requiring neonatal care should be transferred in utero and born at a facility which is able to provide the appropriate level of care. Effective obstetric policies and infrastructure are therefore required
- babies requiring intensive care who are born away from a centre providing this level of care should be transferred to a centre which can provide the care
- babies requiring intensive care should remain at the facility with this designated level of care until it is not longer required
- when babies no longer require the services of intensive care facility, transfer back to a facility with the appropriate level of care should be supported
- numbers of cots available should be based on the following guidelines of 1.1 Level III cots per 1000 live births and 4.25 Level II cots per 1000 live births.
- a Level III unit is required to cater for a catchment area of 10,000 to 25,000 live births (MPEU, 1996).
- integration of neonatal and obstetric services into a perinatal program offers the best opportunity for prevention and treatment (AHMAC).

These guidelines are consistent with the New Zealand guidelines (Liley, 1998).

Projections

The Australian and New Zealand Neonatal Network gathers neonatal data from all Level III units in Australia and New Zealand for babies <32 weeks gestation and <1500 g. This network has now commenced gathering data from Level II units. This data will continue to provide valuable information for future projection in need for neonatal services.

The factors affecting changing patterns of need include:

- improved obstetric confidence in the neonatal care of pre-term infants will increase the number of pre-term infants delivered at earlier stages of gestation
- improved neonatal care will continue to increase the survival rate of low and very low birth weight infants, and for those who do not survive, the interval from birth to death has increased
- increase in multiple births as a result of increased use of assisted conception technologies and rising maternal age.

Broad directions for service development

- That the current service configuration with three Level III units having zonal responsibility be supported for continued clinical effectiveness.
- That the expertise of specialised neonatal paediatricians in larger units continue to be supported to provide the basis for a network, with regionalised services being well linked.
- That the number of births in the Southern Zone be monitored (particularly in view of the services provided to babies born in northern New South Wales) to assess the need for an additional Level III unit.
- That the zonal networks be strengthened through identification and documentation of guidelines for:
  - transferring babies in utero and following delivery into a higher level unit
  - transferring babies back to district hospitals.
- That the role of hospitals with Level III and Level II nurseries be clarified and clearly documented.

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CHAPTER 8: CARDIAC SERVICES

Background

Specialised cardiac services are defined here to include:

- assessment of cardiac conditions using a catheterisation laboratory
- interventions using catheterisation techniques
- cardiac surgery
- implantable cardiac defibrillators (ICD).

In Queensland, the implantation of pacemakers is no longer considered to be a state-wide or a zonal service and is currently provided from a number of facilities in each zone.

Coronary Heart Disease (CHD) produces disabling angina (chest pain) in many patients caused by the progressive narrowing of the blood vessels supplying the heart. Abrupt blockage of a narrowed coronary artery by a blood clot can cause sudden death in many people or can lead to a myocardial infarction (MI) in others. There are three types of interventions available to people with CHD: medical management, percutaneous transluminal coronary angioplasty (PTCA) and coronary artery bypass graft (CABG).

The choice of treatment, either with medication, PTCA or CABG depends on many factors including the severity and location of narrowings in the arteries, the patients' symptoms and preferences, the existence of other medical conditions that influence treatment, the practice patterns of the physicians and the surgeons, and the availability of the services. A diagnostic angiography is performed on patients to assess the choice of treatment particularly to decide between PTCA and CABG.

ICDs are used in the prevention of sudden cardiac death in patients with life-threatening ventricular arrythmias such as sustained ventricular tachycardia (VT) or ventricular fibrillation (VF). There are three major therapeutic options to reduce or prevent VT or VF in patients at risk of arrythmias: antiarrhythmic drug therapy, ablative techniques and ICD devices.

The Cardiac Care Advisory Panel to Queensland Health has recommended the criteria for patients to receive an ICD include the substantial risk of sudden death. Such patients will have been resuscitated from ventricular fibrillation or they will have sustained symptomatic ventricular tachycardia and a left ventricular ejection fraction of 0.40 or less, or will have had unsustained ventricular tachycardia on a background of previous MI, left ventricular dysfunction and inducible, non-suppressible ventricular tacyarrhythmia on electrophysiology study.

Emerging technology

Tridimensional nonfluoroscopic mapping systems (TNMS) are new and emerging technology for the treatment of selected cardiac conditions. These systems can be used by cardiologists to guide the ablation process for focal tachycardia. TNMS provide three dimensional intra cardiac mapping and ablation without using fluoroscopy. These systems use magnetic technology to accurately determine the three dimensional location of the mapping and ablation catheter.

There is a range of disadvantages in using fluoroscopy for cardiology procedures. These disadvantages include low precision in associating intracardiac electrograms with their precise location within the heart and exposure of the patient and medical team to radiation (Gepstein and Evans, 1998). Tridimensional nonfluoroscopic mapping systems aim to overcome these disadvantages.

There are no Queensland hospitals currently using this technology. Only one system is in operation in Australia - a large public hospital in Victoria.

To date there have only been observational studies of this technology in respect of a small number of patients (Nademanee et al, 1998; Stevenson et al, 1998; Leonelli et al, 1998) . However, the results have been encouraging. The largest observational study was in respect of fifteen patients (Joep et al, 1997). This study found that the accurate positioning of the catheter tip was possible without using fluoroscopy and a three dimensional activation map was constructed during sinus rhythm and during supraventricular and ventricular tachycardias of different compartments of the heart.

Whether this technology becomes diffused throughout the public health care sector will depend on the extent to which further evidence is gathered to prove the technology's efficacy.

Referral process

Patients requiring investigation for specialist cardiac care are referred by their general practitioner to a cardiologist who may recommend an angiogram and subsequently decide whether the patient will undergo a PTCA or be referred to a cardiac surgeon for consideration of a CABG. Patients are also referred from emergency departments of public hospitals and patients admitted to public hospitals with conditions such as acute myocardial infarction and unstable angina may also be referred.

Current services

As illustrated in Table 9.1, catheter laboratories are provided throughout the state in both public and private facilities. In total there are 17 cardiac catheter laboratories with seven in the public sector and 10 in the private sector.

Table 9.1 Queensland cardiac catheter laboratories by location

Location	Sector	Number of laboratories
The Prince Charles Hospital	Public	2 (i)
Princess Alexandra Hospital	Public	1 (ii)
Royal Brisbane Hospital	Public	2
Townsville General	Public	1
St Andrews	Private	2
The Wesley Hospital	Private	2
John Flynn Hospital (Gold Coast)	Private	1
Greenslopes Private Hospital	Private	1
Calvary Caims	Private (diagnostic only)	1
The Mater Hospital (Townsville)	Private	1
Allamanda Hospital	Private	1
Andrea Ahem	Private	1
Total		**17**

Note: (i) In addition, the Prince Charles Hospital also has a EP laboratory.
(ii) The second laboratory commenced at the Princess Alexandra Hospital in mid 2001

Source: Queensland Health Procurement Strategy Unit.

Table 9.2 illustrates the public hospitals in Queensland that provide CABG, PTCA and ICDs.

Table 9.2 Public hospitals that provide CABG, PTCA, and ICDs

Hospitals	CABG	PTCA	ICDs
The Prince Charles Hospital	3	3	3
Princess Alexandra Hospital	3	3	-
Townsville General Hospital	3	3	-
Royal Brisbane Hospital	-	3	-

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre

Current activity

Table 9.3 describes the actual number of angiographies, PTCAs and CABGs performed in Queensland hospitals by public and private facility in 1999/00. h 1999/00, 56 per cent of all angiograms were performed in the private sector. This is an increase from 49 per cent in 1995/96. The PTCA rates indicated that in 1999/00 54 per cent of activity was conducted in the private sector compared to a rate of 42 per cent in 1995/96. For CABG, the private sector performed 44 per cent of CABGs in the state, which is a decrease of two per cent from 1995/96.

Table 9.3 **Number of angiographies, PTCAs and CABGs performed in Queensland Health hospitals by public facilities and private facilities in 1999/00**

Facility	Angiographies	PTCAs	CABGs
The Prince Charles Hospital	2732	546	1194
Princess Alexandra Hospital	1238	445	374
Royal Brisbane Hospital	1067	17	-
Townsville General Hospital	788	295	250
Cairns Base Hospital	210	-	-
Total public hospitals	**6035 (44%)**	**1457 (46%)**	**1818 (56%)**
Total private hospitals	**7656 (56%)**	**1708 (54%)**	**1456 (44%)**
Total	13691	3165	3274

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre

Table 9.4 provides directly age standardised rates for angiography, PTCA and CABG performed by zone of usual residence per 100,000 population in all Queensland hospitals.

The rate of angiography is similar in the Central Zone and Southern Zone but is considerably higher in the Northern Zone. The higher rate in the Northern Zone may be explained by the following factors:

- the Southern Zone and Central Zone treat a proportion of patients from interstate and overseas countries, therefore the rates for usual residents for Southern and Central will be lower than the rates of hospitals in that zone. The total capacity of Central and Southern is not reflected in Table 9.4 which does not include interstate and overseas patients
- the Northern Zone has higher proportion of private patients. As demonstrated in Table 9.6 below, the rates of catheterisation and interventions are higher in the privately insured group. Consequently the rates in Northern Zone would be higher
- the Northern Zone has a larger percentage of indigenous people who have a poorer cardiovascular disease health status.

The rate of CABG for residents of Northern Zone and Southern Zone has been decreasing while the rates of CABG for residents of the Central Zone has increased.

The details of changes in rates of PTCA and CABG for residents of each zone are provided in the Table 9.5. There has been an increase in the rate of PTCA from 1995/96 to 1999/00, while CABG rates have remained relatively constant.

Table 9.4 **Directly age-standardised rate of angiography, PTCA and CABG performed by zone of usual residence per 100,000 population in all Queensland hospitals (public & private) in 1999/00**

Diagnosis & Intervention	Northern Zone	Central Zone	Southern Zone
Angiography	494	317	334
PTCA	93	70	84
CABG	103	87	77

Note: These rates do not include interstate and overseas patients.

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Table 9.5 **Rates of PTCA and CABG per 100,000 population per zone in 1995/96 compared to 1999/00 in all Queensland hospitals (public & private)**

Zone	PTCA		CABG	
	Rate in 1995/96	**Rate in 1999/00**	**Rate in 1995/96**	**Rate in 1999/00**
Northern Zone	69	93	121	103
Central Zone	35	70	76	87
Southern Zone	33	84	82	77
Total	**137**	**247**	**279**	**267**

Note: These rates do not distinguish between public and private patients.

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Table 9.6 indicates that privately insured patients have higher rates of diagnostic investigations and cardiac interventions. While the overall rates for Queensland is comparable to benchmark rates, the public/private analysis demonstrates the wide disparity in rates between the two groups.

Table 9 6 1999/00 estimates of coronary procedures by insurance status - directly age-standardised rates per 100,000 population

	Cardiac Catheterisations	PTCA	CABG
1999/00 population rate	377	87	92
1999/00 public patient rate	250	60	71
1999/00 private patient rate	592	132	129

Note: Standardised using the 1991 Australian population.
Denominators estimated using data from the Private Health Insurance Administration Council
These are estimates only, and should be interpreted with caution

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre.

Table 9.7 shows the number of ICDs performed in Queensland Health public hospitals between 1995/96 to 1999/00. In Queensland, all ICDs are performed at The Prince Charles Hospital. These rates are consistent with the Australian average of 30 per million population.

Table 9.7 Number of ICDs performed in Queensland Health public hospitals by facility from 1995/96 to 1999/00

Facility	1995/96	1996/97	1997/98	1998/99	1999/00
The Prince Charles Hospital	27	34	62	72	63

Source: Queensland Hospital Admitted Patient Data Collection – Health Information Centre

Contemporary practice

The use of PTCA has expanded to include patients suffering heart attacks, in combination with, or instead of thrombolytic drugs. When it can be done promptly, PTCA has been shown to be more successful in opening clotted arteries and restoring circulation to the heart with less serious complications than thrombolytic drugs for heart attack patients.

Facilities providing ICD implantation need to provide inpatient and outpatient facilities that should be staffed or supported by a fully trained cardiac electrophysiologist.

Relevant guidelines

The Queensland Health Cardiac Care Advisory Panel endorses the AHMAC, *Superspeciality Services Guidelines for Acute Cardiac Interventions* reported by the Australian Health Technology Advisory Committee (AHMAC, 1995).

In 1998, the Queensland Health Cardiac Care Advisory Panel agreed to a rate of 400 per 100,000 for cardiac catherisation and equal rates of 135 per 100,000 for PTCA and CABG. These rates have subsequently been revised and the accepted targets for Queensland are consistent with guidelines by the Cardiac Care Network of Ontario presented in Table 9.8. These guidelines propose 500 per 100,000 for cardiac catherisation and a ratio of 60:40 for PTCA and CABG (CCNO, 2000).

Table 9.8 Relevant guidelines for cardiac catheterisations, PTCAs and CABGs

Cardiac Catheterisations	PTCA	CABG
500/100,000 Pop initially and 540/100,000 by 2005/06	140/100,000 Pop initially and 160/100,000 by 2005/06	110/100,000 Pop by 2005/06

Source: CCNO, 2000

The need for ICD is difficult to establish as there is variation in published intervention guidelines from five per million in the UK, to 25 per million in Germany and 89 per million for the USA.

Projections

A number of factors are likely to impact on the need for specialist cardiac services in the future. These factors include:

- the ageing population in Queensland
- that while the Queensland rate of cardiac catheterisation and interventions is approaching benchmark levels, the comparative rates of catheterisation and interventions between the public and the private sector means there is potential scope to increase rates in the public sector
- earlier diagnosis of CHD in younger patients leading to PTCA as the preferred treatment for less damaged vessels.

Broad directions for service development

- That prompt and appropriate revascularisation, by an appropriate technique, aiming for a ratio of 60:40 of percutaneous transluminal coronary angioplasty (PTCA) and coronary artery bypass graft (CABG), be provided.

- That the availability of diagnostic cardiac angiography within the public sector increase toward relevant guideline rates.

- Given the rapid advances in technology in this area, that these rates be reviewed in two years.

- That, as the provision of implantable cardioverter defibrillator (ICD) services with trained electrophysiologists is considered to be an essential component of comprehensive specialist cardiac care services, consideration be given to redistributing the workload between the Prince Charles Hospital and the Princess Alexandra Hospital rather than increasing the number of ICDs substantially.

- That an ICD service in the Northern Zone, is not indicated at present, and should be considered as part of longer term planning if demand changes.

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