This document is Part 1 of a three-part set as follows:

- **Part 1** – Guidance for Established NFCs (governance, management, funding and review)
- **Part 2** – Guidance for Proposed NFCs (nomination, assessment, site selection and establishment)
- **Part 3** – Guidance for pricing the NFC Episode of Care and the NFC Costing Pro Forma


Enquiries in regards to the NFC Program should be made in the first instance to your relevant jurisdictional department of health. A current list of jurisdictional Nationally Funded Centres Reference Group members can be found at [www.nfc.sa.gov.au](http://www.nfc.sa.gov.au).
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October 2015
CHAPTER 1: INTRODUCTION

1.1. PURPOSE OF THIS DOCUMENT

The purpose of this document is to ensure that there is accountability and transparency in Nationally Funded Centres (NFC) processes and to provide guidance for NFC Reference Group members, host jurisdictions, NFC sites and other stakeholders with an interest in the delivery, management and administration of the program.

In summary, this document provides guidance on:
• the governance, management, administration and funding of the NFC Program;
• the governance, management, administration and funding of NFC sites;
• the process of reviewing established NFCs; and
• the cessation of a NFC.


For information on establishing the price for a NFC episode of care and guidance on the costs to be taken into consideration in establishing a price, refer to the NFC Guidance Document – Part 3, available at www.nfc.sa.gov.au.

1.2. PROGRAM OBJECTIVES

The NFC Program provides a national policy and funding framework for the efficient and effective delivery of certain high cost, highly specialised health technologies with limited demand, to optimise access for all Australians. For a technology to be considered for NFC status it must require a national population base for efficient and effective service provision.

The objectives of the NFC Program are to ensure that:
• there is optimal access to certain high cost, low demand, new and emerging technologies regardless of geographical location, in the context of workforce and resource availability;
• these technologies are provided efficiently and effectively;
• requirements for high quality and safe introduction and ongoing provision of these technologies have been defined and implemented; and
• health and cost outcomes of these technologies are monitored and evaluated.

1.3. PROGRAM BACKGROUND AND GOVERNANCE

In June 1990 Australian health ministers (now meeting as the Council of Australian Governments (COAG) Health Council) endorsed a national policy for public sector provision of certain high cost, highly specialised clinical practices and technologies with limited demand. This is the Nationally Funded Centres (NFC) Program.

The health ministers assigned oversight of all aspects of the program and its associated policy to the Australian Health Ministers’ Advisory Council (AHMAC).
The NFC Reference Group was established by AHMAC to manage the NFC Program. The NFC Reference Group reports to the AHMAC through AHMAC’s Hospitals Principal Committee (HPC).

Administration of the NFC Program is undertaken by a host jurisdiction nominated by AHMAC. The host jurisdiction will establish a NFC Reference Group Secretariat (the NFC Secretariat) for this purpose. The NFC Secretariat is currently hosted by the Department for Health and Ageing, South Australia.

Refer to the next section (1.4 ‘Roles and responsibilities’) for more information on these bodies.

Figure 1. NFC Program governance structure

![NFC Program governance structure diagram]

1.4 Roles and Responsibilities

COAG Health Council

The COAG (Council of Australian Governments) Health Council is a meeting of all Australian Health Ministers and provides a forum for continued cooperation between the Commonwealth and the states and territories on health issues. It is involved in the development of national strategy, policy and standards. The COAG Health Council was formerly known as the Standing Council on Health (SCoH) and prior to that the Australian Health Ministers’ Conference (AHMC).

The COAG Health Council (at the time known as the AHMC) assigned oversight of all aspects of the NFC Program and its associated policy to the Australian Health Ministers’ Advisory Council (AHMAC) and it is only on rare occasions that AHMAC will report to the COAG Health Council on NFC matters, and usually only for noting significant changes or emerging issues.
Australian Health Ministers’ Advisory Council
The Australian Health Ministers’ Advisory Council (AHMAC) is the advisory and support body to the COAG Health Council, advising them on strategic issues relating to the coordination of health services across the nation and operating as a national forum for planning, information sharing and innovation.

The COAG Health Council assigned oversight of all aspects of the NFC Program and associated policy to the AHMAC and all policy and procedural matters relating to the NFC program are considered by AHMAC for their approval. AHMAC members may also note NFC related matters for information rather than approval.

For more information about AHMAC, refer to the COAG Health Council website at: http://www.coaghealthcouncil.gov.au/

Hospitals Principal Committee
The Hospitals Principal Committee (HPC) is an advisory and support body to the AHMAC. The NFC Reference Group reports to AHMAC through its HPC. For more information about the HPC refer to the Principal Committees link on the COAG Health Council website at: http://www.coaghealthcouncil.gov.au/

Nationally Funded Centres (NFC) Reference Group
The NFC Reference Group is established by AHMAC and comprises of a representative from each state and territory and the Australian Government.

The NFC Reference Group reports to AHMAC through the HPC and is responsible for:

• planning and management of the NFC Program;
• considering nominations for NFC status and where appropriate, assessing the technologies nominated;
• undertaking the review of established NFCs every three years, or at other times as approved by AHMAC;
• making recommendations to AHMAC regarding proposals for new technologies;
• making recommendations to AHMAC regarding the outcome of reviews of established NFCs;
• determining the annual operating budgets for approved NFCs and for the general administration of the NFC Program in accordance with AHMAC-approved NFC policies; and
• developing and maintaining interfaces with relevant bodies including HealthPACT and the Australian Organ and Tissue Authority in order to optimise effective consideration of health technology issues and avoid duplication of effort.

The NFC Reference Group works with NFC sites through their jurisdictional NFC Reference Group member.

NFC sites report to the NFC Reference Group through their jurisdictional NFC Reference Group member.

The NFC Reference Group will meet as required and can invite attendees to meetings as deemed appropriate on a meeting by meeting basis.
The NFC Reference Group coordinates a biennial Clinicians’ Workshop where it meets with clinicians from the NFC sites to discuss current issues and process improvements. The outcomes of these workshops (held in February every second year) influence the NFC Reference Group’s work plan for the next financial year.

For a list of the NFC Reference Group members and their contact details refer to www.nfc.sa.gov.au.

Nationally Funded Centres (NFC) Reference Group Secretariat
Administration of the NFC Program is undertaken by a host jurisdiction nominated by AHMAC. The host jurisdiction will establish a NFC Reference Group Secretariat (the NFC Secretariat) for this purpose. The Secretariat is currently hosted by the Department for Health and Ageing, South Australia.

The NFC Secretariat is responsible for providing the NFC Reference Group with administrative support for:
- NFC assessments and reviews;
- the annual budget process, including the collection and analysis of data;
- routine reviews and updates of the Guidance document for the NFC Program in consultation with the Australian Government, the States, Territories and NFC units;
- all NFC Reference Group meetings;
- the clinician’s workshop and NFC Reference Group meeting to be held in February every second year; and
- a national website for the NFC Program.

For contact details for the NFC Secretariat refer to www.nfc.sa.gov.au.

State and Territory Health Departments
The role of the State and Territory health departments is to:
- nominate a jurisdictional representative to be a member of the NFC Reference Group;
- participate in NFC processes, including health technology assessments and NFC technology review processes;
- host designated NFC services in accordance with the agreed NFC Guidance document;
- cooperate with all other states and territories in the provision of NFC services regardless of whether they are host or non host states and territories; and
- contribute to the NFC Program budget in accordance with the AHMAC-approved allocation mechanism.

Australian Government, Department of Health
The role of the Australian Government is to nominate a representative to the NFC Reference Group. Through that representation and consultation, the Australian Government will participate in NFC processes, including health technology assessments, NFC technology reviews, policy discussions and general management of the NFC Program.
CHAPTER 2: FEATURES OF NFC TECHNOLOGIES AND NFC STATUS

2.1 PROGRAM ELIGIBILITY AND SCOPE

For a technology to be considered for NFC status it must require a national population base for efficient and effective service provision, and:
• it must be an established clinical practice; or
• a clinical practice in the establishment phase, yet to be incorporated into standard clinical practice but with the potential for broader diffusion into the Australian health system.

Once a NFC site is established, the NFC services it provides are made available to all Australians, with equitable patient acceptance criteria and funding to improve patient access (i.e. to support the transport and accommodation needs of interstate patients and a family member or carer for the usual pathway for these patients).

A clear definition of the start and end point for an episode of care is determined on establishment of each new NFC technology. In general, the referring jurisdiction will pay for the patient until the patient is admitted for the definitive NFC treatment or procedure. The NFC Program will then pay for the patient costs until three months post discharge, after which the referring jurisdiction will again be responsible. There may be exceptions to this general scope as approved by AHMAC on establishment of a new NFC technology, as deemed appropriate for the particular technology being funded under the program.

2.2 RANGE OF TECHNOLOGIES

The range of technologies eligible for consideration as a NFC includes devices, prostheses, techniques, skills or expertise (or personnel with particular skills or expertise) and/or procedures, or combinations of these.

High cost, low demand pharmaceuticals are not eligible except as an essential component of care in the provision of a particular practice or technology (excluding s100 pharmaceuticals).

2.3 SERVICE CONCENTRATION

The overarching principle in considering a technology for provision as a NFC is that it must require a national population base for efficient and effective service provision (i.e. there is a need to concentrate the service in order to increase activity at the selected site (or sites) to maximise the quality of outcomes).

There is an expectation that a technology funded under the NFC Program will only be provided in Australia through approved NFC sites. States and territories are expected to discourage the proliferation of an NFC technology across other health services within their jurisdictions. A state or territory cannot renege on funding their share of the NFC Program if they elect to provide the technology at a site other than an approved NFC site.
2.4 **Variation to AHMAC-approved conditions**

Any potential or proposed change in the AHMAC-approved NFC service (e.g. patient pathway, patient selection criteria, model of care, etc) must be brought to the attention of the relevant jurisdictional NFC Reference Group member for consideration by the NFC Reference Group before the NFC site implements the change. The NFC site may not be eligible for funding for activity undertaken under changed conditions and should wait for advice from the NFC Reference Group before undertaking NFC activity under those changed conditions.

The NFC Reference Group will give consideration to funding activity that varies from the AHMAC-approved pathway or model of care under the NFC Program on a case by case basis or, if practicable or necessary, agree to defer consideration to the next scheduled review of the particular technology.

2.5 **Duration of NFC status**

All NFC technologies are reviewed on a regular basis (in general every three years) in order to, among other things, determine if the technology is still eligible for NFC status. Refer to Chapter 5 for more information on reviews of established NFCs and Chapter 6 for more information on the cessation of NFC status.

Some technologies will be provided under the NFC Program long-term, whilst others will be for a shorter term as the practice becomes more established and diffusion across the health system becomes appropriate. In some instances, new evidence may become available to determine that a technology should no longer be designated as a NFC for reasons that were unknown at the time of approval.

2.6 **Overseas patients**

NFC sites may provide services to overseas residents if this does not impede access for Australian residents.

Overseas residents will be charged the full cost of the service, subject to any reciprocal arrangements between Australia and an overseas country (i.e. relating to the need for immediate and necessary care) agreed with the overseas country. If reciprocal arrangements exist and apply to the circumstances and the treatment received by the overseas patient, then the activity can be counted as NFC activity and will be funded under the NFC Program. Where a funding claim for an overseas resident is made under the NFC Program, the site and host jurisdiction must provide necessary clinical and administrative details to the satisfaction of the NFC Reference Group.

In general, overseas residents residing in Australia and enrolled in Medicare are to be treated as Medicare eligible Australian residents (they must have a valid (in date) Medicare number). However final approval of eligibility will be given on a case by case basis by the NFC Reference Group.
CHAPTER 3:  BUDGET AND FUNDING

3.1 NFC PROGRAM BUDGET

The NFC Reference Group calculates the NFC Program budget on an annual basis for the delivery of:
- approved NFC activity;
- planned assessments and reviews in a given financial year; and
- the operations of the NFC Secretariat.

If there is more than one NFC site providing the same technology, each site will receive the same price per episode of care. The price is indexed annually by an amount reflecting the Australian Institute of Health and Welfare health-specific cost index and the Productivity Commission derived index of technology growth, as used for the National Healthcare Agreement growth factor.

The source of funds for the NFC Program is contributions from the states and territories based on their population share of the total NFC Program budget. Treasury raw population estimates, which are published in the Commonwealth budget papers in May each year (under Appendix A: Parameters and Further Information), are used for this purpose.

3.2 NFC PROGRAM FUNDING

The host jurisdictions receive the funding for the activity their NFC sites provide under this national program. (Refer to item 3.3. below under ‘Steps of the annual budget cycle’ for more detail.)

The amount provided to a host jurisdiction is an advance for the estimated activity that their NFC site or sites will undertake in a financial year, at the AHMAC-approved price for the delivery of the particular technology under the NFC Program. The amount paid by the NFC Program may be increased or reduced following a reconciliation of the previous years’ advance for estimated activity against that years’ actual activity.

The host jurisdiction will distribute NFC Program funding to their NFC site or sites in accordance with local arrangements.


3.3 STEPS OF THE ANNUAL BUDGET CYCLE

- Post 30 June, each NFC site will submit an annual report (NFC Annual Statistical Return, Annual Report and Activity Plan) which includes data on the actual number of procedures performed in the financial year just ended and estimated activity for the new financial year. Refer to Appendix 1.1 for a pro forma of the NFC Annual Statistical Return, Annual Report and Activity Plan.
The NFC Secretariat prepares the NFC Program budget in accordance with AHMAC-approved NFC policies (for NFC activity, any planned reviews or assessments and funding for the NFC Secretariat) and presents the budget to the NFC Reference Group.

All jurisdictions are asked to endorse the budget and to seek appropriate delegate approval for their financial contribution to the budget.

Following jurisdictional endorsement of the budget and jurisdictional contributions:

- the NFC Reference Group will advise AHMAC, through HPC, of the approved budget at the earliest appropriate opportunity; and

- the NFC Secretariat will arrange for the collection of each jurisdiction’s contribution (these contributions are held by the AHMAC Secretariat on behalf of the NFC Program).

Once all jurisdictions have paid their contribution to the year’s NFC activity, host jurisdictions will be funded for the activity their NFC sites provide under this national program. By arrangement with the NFC Secretariat, one of the following may occur:

- a host jurisdiction may choose to receive a payment for the full entitlement relating to their NFC activity (and separately pay to the NFC Program their population share of total NFC activity); or

- a host jurisdiction may choose to receive a payment for a net amount calculated on the amount they are entitled to for the NFC activity they provide, less the amount they owe to the NFC Program for their population share of the cost of total NFC activity (where the amount the jurisdiction owes is the lesser amount); or

- a host jurisdiction may choose not to receive any payment but instead reduce the amount they pay to the NFC Program for their population share of the cost of total NFC activity, by the amount they are entitled to for the NFC activity they provide (where the amount the jurisdiction is owed is the lesser amount).

The host jurisdiction will distribute NFC Program funding to their NFC site or sites in accordance with local arrangements.

Once jurisdictions have paid their contributions to the operating costs of the NFC Secretariat, the amount agreed in the budget will be transferred to the host jurisdiction as a one off payment per annum.

Once jurisdictions have paid their contributions to the planned assessments and/or reviews (if any), the agreed budget amounts will be held by the AHMAC Secretariat and invoices for services provided for those assessments and/or reviews will be paid directly from the AHMAC account at the direction of the NFC Reference Group Chair (in accordance with agreed milestones of individual reviews or assessments).
CHAPTER 4: REPORTING REQUIREMENTS

4.1. **Annual Statistical Return, Annual Report and Activity Plan**

**Annual report pro forma and submitting an annual report**

A pro forma of the NFC Annual Statistical Return, Annual Report and Activity Plan (annual report) is available at Appendix 1.1.

The NFC Reference Group will develop a specific annual report for each NFC technology on establishment of that technology as a NFC. Annual report pro formas may differ between NFC technologies, but will be the same for each site delivering the same technology.

Every NFC site is required to submit an annual report on a financial year basis, within three weeks of the close of the financial year.

Each site’s annual report must be submitted to the NFC Reference Group via their host jurisdictional NFC Reference Group member and/or health department. The host jurisdiction must be satisfied that the annual report is complete and accurate before forwarding it to the NFC Reference Group.

Information collected in the annual reports is aggregated by the NFC Secretariat for reporting to the NFC Reference Group. The aggregated information is also presented against information collected in earlier years for comparative purposes.

**Annual reporting on activity**

Each site’s annual report includes a report on activity (actual activity for the reporting period and estimated activity for the new financial year). This activity information is used to calculate the number of eligible procedures payable for each NFC.

Where an episode of care under the NFC Program straddles two financial years, the date the definitive NFC procedure is undertaken is the date used to determine the financial year that applies for annual reporting and funding purposes. The NFC Reference Group may approve variations to this general rule on a case by case basis, but the site will be required to apply the variation consistently from year to year. If in doubt, the site should seek clarification from the NFC Reference Group via their jurisdictional representative (a list of jurisdictional representatives is available at www.nfc.sa.gov.au).

While each NFC technology will have a tailored annual report, the activity information sought is generally as follows:

- patient referrals and home jurisdictions (number of referrals, whether accepted or not accepted, etc);
- for paediatric programs, patients’ ages;
- the status of accepted patients at the end of the reporting period (treated, awaiting treatment);
- actual activity data for the last financial year;
- activity plans (estimated) for the upcoming financial year.
**Annual reporting on outcomes**
The annual report includes a variety of measurements to evaluate the quality of outcomes at the NFC site.

These measures are determined in consultation with host jurisdictions and advised to NFC sites on establishment. In nominating for consideration of NFC status, jurisdictions and sites are required to identify the health outcomes to be achieved from the technology (i.e. the measures of success and how they will be measured).

Outcome measures may vary during the life of a NFC but changes must be agreed to by the NFC Reference Group and the host jurisdiction (in consultation with sites) at the beginning of the financial year for which the data is to be collected.

While each NFC technology will have a tailored annual report, the outcomes information sought is generally as follows:
- the status of accepted patients at the end of the reporting period (treated, awaiting treatment);
- patient journey;
- type of patient outcomes;
- quality measures;
- patient and/or transplant survival figures;
- progress on recommendations from the health technology assessment or latest review as applicable.

**Reporting on changes in costs**
The annual report provides an opportunity for NFC sites to identify significant changes in costs that the site feels should be addressed before the next scheduled review of the NFC technology. This allows the NFC Reference Group to proactively monitor changes in costs as part of the annual reporting by NFCs.


**Reporting on changes in technology**
The annual report requires NFC sites to identify potential and/or proposed changes in the technology. This allows the NFC Reference Group to proactively monitor changes in technology as part of the annual reporting by NFCs.

Any potential or proposed change in the AHMAC-approved NFC service (e.g. patient pathway, patient selection criteria, model of care, etc) must be approved by the NFC Reference Group (and potentially by AHMAC) before the NFC site implements the changes. If changes to an existing AHMAC-approved NFC service are not approved, the site may not be eligible for funding for activity undertaken under those changed conditions.

The NFC Reference Group will give consideration to funding activity that varies from the AHMAC-approved pathway or model of care under the NFC Program on a case by case basis or, if practicable or necessary, agree to defer consideration to the next scheduled review of the particular technology.
4.2. **NFC Patient and Family Questionnaire**

The NFC Patient and Family Questionnaire is intended to provide NFC patients and/or their families/carers with an opportunity to give their views on how their care, or the care of a family member, was managed under the NFC Program.

The aim of the questionnaire is to contribute to continuous improvement and development of the NFC Program and not for rating or assessing individual NFC sites or clinicians.

The questionnaire can be completed by the patient and/or members of the patient’s family and/or the patient’s carer. Completing the questionnaire is voluntary.

The number of patients in the NFC Program is relatively small and this raises the potential for patients to be more easily identified. The NFC Reference Group endeavours to maintain confidentiality for respondents.

The information collected is aggregated by the NFC Secretariat by calendar year for reporting to the NFC Reference Group. Jurisdictional NFC Reference Group members from host jurisdictions will use the annual reports to discuss opportunities for improvements with their NFC sites. A summary of aggregated responses will be provided to a reviewing body to inform the review of a NFC technology (for more information on the review of established NFCs, refer to Chapter 5).

NFC sites are to make the questionnaire available to all patients (and/or their family/carer) treated under the NFC Program by providing two copies of the questionnaire, along with a pre-paid envelope (addressed to the NFC Secretariat) to each patient (and/or their family/carer) on discharge from the NFC Program. While it is intended that this is done on discharge from the NFC Program, it is left to the discretion of each NFC site to determine the appropriate timing on a patient by patient basis.

Stocks of the pre-paid envelopes are available from the site’s jurisdictional NFC Reference Group member. Copies of the questionnaire and a current list of jurisdictional members can be found at [www.nfc.sa.gov.au](http://www.nfc.sa.gov.au).

A copy of the NFC Patient and Family Questionnaire is available at Appendix 1.2.
CHAPTER 5: REVIEWS OF ESTABLISHED NFCs

5.1 SCHEDULING REVIEWS OF ESTABLISHED NFCs

Timing of regular reviews
All NFC technologies are reviewed on a regular basis.

As part of the establishment of a new NFC technology the NFC Reference Group will recommend a review period to AHMAC which, in general, will be three years after establishment. However the NFC Reference Group may recommend that the first review is undertaken at an earlier time or in an extended period (up to a maximum of five years).

Established NFCs are also scheduled to be reviewed every three years. Again, the NFC Reference Group may seek approval from AHMAC for a variation to the three-year cycle.

The NFC Reference Group may seek approval from AHMAC to undertake a review before the three-year review process where:
- the technology has changed more quickly than anticipated (i.e. the NFC may no longer be required or the scope of the services has been impacted);
- changes have resulted in a significant cost increase or decrease;
- some other unforseen issue has arisen or new information has been provided.

The NFC Reference Group may seek approval from AHMAC to undertake a review after an extended period, up to a maximum of five years, where:
- there is a view that the technology will not change for the extended period; and
- the quality of the information being provided in the annual reports is satisfactory to monitor the NFC between reviews.

It is noted that extending the period between reviews will achieve a reduction in administrative and compliance costs for the NFC Reference Group, the host jurisdiction and the NFC sites. However, an extension to the review period must not compromise the quality of outcomes or patient safety.

AHMAC request for review
In exceptional circumstances AHMAC may make a specific request for a review of a current NFC technology and provide funding for that review.

Requesting a price review
On behalf of a NFC site, a host jurisdiction may request a review of the cost of delivering a NFC technology prior to the three-year review process where material changes have occurred (e.g. new technology has resulted in significant modifications to the treatment being provided). The request should be made to the NFC Reference Group through the jurisdictional representative.

A price review will be considered in the first instance by the NFC Reference Group, with expert advice to be sought as required. If as a result of the review a new price is supported by the NFC Reference Group, and subsequently approved by AHMAC, the new price will apply in the next NFC annual budget cycle.
5.2 **THE REVIEW OBJECTIVES**

The primary objective of a review of an established NFC technology is to provide a comprehensive analysis of the delivery of the technology under the NFC Program to inform a recommendation as to its ongoing eligibility for NFC status, in accordance with AHMAC-approved NFC policies and the objectives of the NFC Program.

A recommendation for NFC status to be withdrawn will take effect on the 30 June in the next calendar year from the date that recommendation is approved by AHMAC (refer Chapter 6).

If ongoing NFC status is recommended, then the review report will also include a recommendation on the number of sites that should deliver the technology (i.e. the same number, or more, or less sites) and an appropriate price to be paid for the delivery of that technology under the NFC Program.

A recommendation may be made to AHMAC to increase the number of NFC providers if it is shown that:

- satisfactory health and cost-effectiveness outcomes have been achieved at a new site; and/or
- the existing site or sites do not have the capacity to meet the needs of the Australian population for the foreseeable future; and/or
- international demand and benchmarks for volume/quality relationships support further expansion; and/or
- the cost effectiveness of an additional site(s) is similar to that of the existing site(s); and/or
- the establishment of an additional site(s) will not adversely affect health outcomes; equity of access; or cost effectiveness.

In considering the number of sites, a balance needs to be reached between ensuring optimal access to the service for all Australians, with the need to ensure that expansion of the number of NFC providers does not result in inefficiencies, dilution of expertise, or reduction in the quality of outcomes.

The review will also recommend improvements to the delivery of technology as identified during the course of the review such as:

- recommendations to the NFC Reference Group or the NFC site(s) to address and rectify issues identified by the reviewing body, and / or
- recommendations to the NFC Reference Group to modify the scope of services and care provided by the NFC to meet current clinical and service requirements.

Refinement of the scope of the review may be required after commencement of the review. This may be facilitated through out of session agreement between the NFC Reference Group and the reviewing body.

The recommendations of the review report must only reflect the agreed scope of the review however, comments regarding issues outside of the scope may be included in the body of the final report if the reviewer determines that their inclusion is warranted.

The reviewing body will use the review criteria listed in Appendix 1.3.
5.3 **Criteria for the Review**

Criteria to be considered as part of a review are listed in Appendix 1.3 and include:

- access to the NFC (including clear criteria for patient selection and, where they do not exist, a recommendation that such criteria be developed);
- health outcomes;
- model of care and service delivery;
- quality and safety;
- teaching, training and research;
- changes to clinical practice;
- service demand;
- cost; and
- risk management.

The need for, and benefits of, continued service concentration will be considered taking into account the above information and including, but not limited to:

- health outcomes achieved to date;
- new evidence on effectiveness of the existing technology and development of existing comparator treatments;
- estimates of the national demand for the technology and national and international evidence of a volume/quality relationship
- international practice;
- equity of access to the technology; and
- cost.

Issues such as optimal throughput and critical mass to determine the number of sites and the point at which additional or fewer sites are required should also be addressed. Other factors to be considered in determining appropriate number of sites will include improving patient access and maintaining sufficient throughput at the existing NFC units to ensure maintenance of skills and efficiency in service provision.

5.4 **Price per Episode of Care**

A clear definition of the start and end point for an episode of care is determined on establishment of each new NFC technology. In general, the referring jurisdiction will pay for the patient until the patient is admitted for the definitive NFC treatment or procedure. The NFC Program will then pay for the patient costs until three months post discharge, after which the referring jurisdiction will again be responsible. There may be exceptions to this general scope as approved by AHMAC on establishment of a new NFC technology, as deemed appropriate for the particular technology being funded under the program.

The price per episode of care will be reviewed on the basis of the AHMAC-approved care pathways and costings as presented by the NFC sites using the NFC Costing Pro Forma in the NFC Guidance document – Part 3.

For more information on the price per episode of care refer to the NFC Guidance document – Part 3 (available at [www.nfc.sa.gov.au](http://www.nfc.sa.gov.au)).
5.5 MANAGING AND CONDUCTING A REVIEW

The NFC Reference Group will nominate three of its members to act on its behalf throughout the review. This project management group will manage the selection process to engage a reviewing body and, following that engagement, will manage the review.

Project management group members are required to declare to the NFC Reference Group in writing if they have any potential conflicts of interest in relation to their role on a project management group.

The role of the project management group will include:
- evaluating tenders for the review against agreed evaluation criteria;
- reviewing and endorsing reports prepared on their behalf by the NFC Secretariat including a procurement report/purchase recommendation for the engagement of the consultant; and
- project managing the review from commencement of the consultancy to final report stage including:
  - agreeing a work plan with the consultants;
  - assessing and agreeing the achievement of milestones for approval of progress payments to consultants;
  - accompanying the consultants to site visits (at least one project management group member per visit); and
  - ensuring regular reporting to the NFC Reference Group on the progress of the review.

The NFC Secretariat will provide administrative support and act as liaison between the reviewing body and the project management group.

The reviewing body will visit relevant sites for the technology being reviewed as specified in the agreed work plan and a member of the project management group will be invited to each site visit.

5.6 ENGAGEMENT OF A REVIEWING BODY

A reviewing body is an independent consultant organisation engaged by the NFC Reference Group on behalf of AHMAC to undertake a review of an established NFC technology as required.

The procurement process for the engagement of a reviewing body will comply with the relevant policies of the jurisdiction tasked with administering the procurement (which will usually be the jurisdiction hosting the NFC Secretariat).

The reviewing body will comprise evaluators with significant experience in this type of work including personnel with expertise in the clinical specialty, health services planning, health economics and technology assessment. The NFC Reference Group will take into account expertise and ability, track record, quality of the work, value for money and timeframes in selecting the preferred reviewing body.

Given the specialised nature of NFC technologies and to ensure independent clinical input into the review and review outcomes, the reviewing body will be encouraged to arrange for input from experts in the field, both from an international and a domestic viewpoint.
From an international perspective, independent review by an international expert living and working overseas is preferred; however someone with recent and relevant international experience (within the last five years) would be suitable if a level of independence can be ascertained. From a domestic perspective, input from an independent clinician with experience in delivery of the technology within the Australian health system is also encouraged.

The NFC Reference Group will negotiate with the reviewing body and agree a work plan for the review, including the structure of the process, roles, responsibilities, reporting, timelines and consultation. These negotiations should ensure that the scope of the work is clearly understood by the reviewing body.

The reviewing body will be expected to visit relevant sites for the technology being reviewed as specified in the agreed work plan. NFC sites and host jurisdictions will be asked to participate in the site visits.

5.7 **RESPONSIBILITIES OF THE HOST JURISDICTIONS AND NFC SITES**

NFC sites are required to:
- submit a report addressing the review criteria (refer Appendix 1.3);
- supply updated costing details in accordance with the NFC Costing Pro Forma (refer to the NFC Guidance document – Part 3, available at www.nfc.sa.gov.au);
- provide contact details of relevant parties for stakeholder consultation;
- facilitate access to patients and families willing to participate in stakeholder consultation; and
- host site visits by the reviewing body, the jurisdictional NFC Reference Group member and a member of the project management group.

Host jurisdictions are required to:
- work with their NFC site to address the review criteria (refer to Appendix 1.3);
- work with their NFC sites to supply updated costing details in accordance with the NFC Costing Pro Forma (refer to the NFC Guidance document – Part 3, available at www.nfc.sa.gov.au);
- ensure that the data provided for the review process is accurate; and
- participate in the site visits by the reviewing body.

In developing and presenting information, jurisdictions will need to be mindful of the fact that where numbers are small, there is the potential for patients to be identifiable. The need for patient privacy may be more acute.

5.8 **INFORMATION SUPPLIED TO THE REVIEWING BODY**

At the commencement of the review the NFC Secretariat will provide the reviewing body with the following information:
- site annual reports since last review (or since establishment, if this is the first review);
- relevant annual report analysis tables as prepared by the NFC Secretariat annually;
- a summary of NFC Patient and Family Questionnaire responses for the review period;
- information from sites (Appendix 1.3 and costing details from the NFC Guidance document – Part 3); and
- a list of jurisdictional contacts for stakeholder consultation.
The NFC Secretariat will seek jurisdictional nominees for stakeholder consultation (from provider sites and referring jurisdictions) during the review and will provide a list of stakeholders to the reviewing body.

5.9 **SUMMARY OF REVIEW REPORT**

The process for commenting on and finalising the review report will be as follows:

- a final draft with recommendations will be referred to NFC Reference Group members by the project management group for comment from a jurisdictional and NFC Program perspective;
- the NFC Reference Group members will circulate the report to interested parties within their jurisdiction for comment, including comments on information included in the report, discussion items, observations made and the recommendations;
- the NFC Secretariat will collate the comments and refer them to the reviewing body to enable the reviewing body to finalise their report;
- the reviewing body is required to consider all comments and provides jurisdictions with a formal response to their comments;
- NFC Reference Group members will receive a final draft incorporating feedback for final comment which will again be collated by the NFC Secretariat;
- the reviewing body will finalise their report and formally refer it to the NFC Reference Group.

5.10 **REVIEW FINDINGS AND IMPLEMENTATION OF REVIEW FINDINGS**

Based on the recommendations of the reviewing body and consideration of other factors as appropriate, the NFC Reference Group will present a paper to AHMAC (through HPC) on the NFC Reference Group’s proposed way forward on the recommendations in the review report (including any dissenting views).

If the technology is recommended for ongoing NFC status, the recommendations will also include the recommended number of sites and a view of the performance and suitability of the current site or sites. The report will also recommend a price for the technology under the NFC Program.

If ongoing NFC status is approved, the NFC Reference Group will:

- write to the host jurisdiction or jurisdictions outlining AHMAC-approved outcomes;
- write to the other jurisdictions advising them of the outcome;
- advise the consultant(s) that the review has been finalised;
- include any recommendations for the attention of the NFC Reference Group on the NFC Reference Group’s work plan;
- incorporate recommendations assigned to the site or sites within the site annual reports to ensure regular reporting on progress.

The proposal to AHMAC will include any special conditions for the NFC and the appropriate agreed date for next review (usually three years after approval).

If ongoing NFC status is not approved, the NFC Reference Group will write to the host jurisdiction or jurisdictions advising them of the outcome and the reasons for the decision. (Refer to Chapter 6.)
CHAPTER 6: CESSATION OF NFC STATUS

At some point in the provision of a specific NFC technology, agreement may be reached by AHMAC that NFC status is no longer appropriate. This point may be reached when:

- there is no longer any need for a NFC as the technology is provided in the majority of jurisdictions; or
- the technology has been superseded by another clinical practice.

If NFC status is withdrawn, the NFC Reference Group will write to the host jurisdiction or jurisdictions advising them of this decision and the reasons for the decision.

Where AHMAC approves the withdrawal of NFC status, the affected site or sites will cease as a NFC effective by 30 June in the next calendar year following the AHMAC decision.

If at this point some states and/or territories are still not providing the service, then the usual arrangements for state and territory cross border activity will apply.

Sites may choose to continue to collaborate as appropriate and/or continue a centralised data collection for the service outside of the NFC Program.
20XX-XX ANNUAL STATISTICAL RETURN AND ANNUAL REPORT
AND
20XX-XX ACTIVITY PLAN
NATIONALLY FUNDED CENTRES (NFC) PROGRAM

This is to be completed annually and forwarded to the NFC Reference Group via the NFC Secretariat by the 15th working day after 1 July of each year.

Name of NFC: ______________________________________________

State / Territory: ______________________________________________

Health Service / Hospital: _______________________________________

_____________________________________________________________________

1. Summary information of patient numbers

TABLE 1.1 New referrals during 20XX-XX

<table>
<thead>
<tr>
<th>State or Territory of patient’s residence</th>
<th>New referrals</th>
<th>Accepted</th>
<th>Not accepted</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VIC</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>QLD</td>
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<td>WA</td>
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<tr>
<td>SA</td>
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<td></td>
<td></td>
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<tr>
<td>TAS</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>ACT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NT</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overseas (advise country), refer Section 2.6 of NFC Guidance document</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Patients may be actively undergoing assessment to determine whether suitable for acceptance on waiting list.
TABLE 1.2: Status of 20XX-XX patients*

<table>
<thead>
<tr>
<th>State or territory of patient residence</th>
<th>Awaiting Treatment</th>
<th>Treated</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Accepted this year</td>
<td>Accepted previous year(s)</td>
</tr>
<tr>
<td></td>
<td>A</td>
<td>B</td>
</tr>
<tr>
<td></td>
<td>C</td>
<td>D</td>
</tr>
<tr>
<td>NSW</td>
<td></td>
<td></td>
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<tr>
<td>VIC</td>
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<td>QLD</td>
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<tr>
<td>WA</td>
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<td></td>
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<tr>
<td>SA</td>
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<tr>
<td>TAS</td>
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<tr>
<td>ACT</td>
<td></td>
<td></td>
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<tr>
<td>NT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overseas (advise country)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refer Section 2.6 of the NFC Guidance document</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* All patients to be identified for the 20XX-XX reporting year irrespective of awaiting treatment, treated or treatment outcome. This should also include death while awaiting treatment and post treatment.

TABLE 1.3: Discharges from NFC in 20XX-XX*

<table>
<thead>
<tr>
<th>State or Territory</th>
<th>Patients accepted that do not proceed to treatment</th>
<th>Patients accepted and treated that do not proceed to discharge</th>
<th>Patients accepted, treated and discharged</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number exiting while awaiting treatment due to death</td>
<td>Number exiting while awaiting treatment due to causes other than death</td>
<td>Number of treated patients exiting before discharge from the NFC (i.e. exiting at three months post discharge from hospital)</td>
</tr>
<tr>
<td>NSW</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VIC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>QLD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WA</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>SA</td>
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<td>TAS</td>
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<tr>
<td>ACT</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>NT</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>SA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overseas (advise country)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Discharge is at the point where the ongoing care of the patient is no longer provided by the NFC.
### TABLE 1.4: Types of patient outcomes in 20XX-XX*

<table>
<thead>
<tr>
<th>Type</th>
<th>No. of patient outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients with expected care pathway and clinical progress</td>
<td></td>
</tr>
<tr>
<td>Patients with complicated care pathway and clinical progress</td>
<td></td>
</tr>
<tr>
<td>Death post treatment</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
</tr>
</tbody>
</table>

* The total number of patients should equal the sum of patients in columns C + D in Table 1.2.

2. **Quality measures – 20XX-XX**

Provide information on the patient outcomes, and clinical quality and safety indicators for the technology for the year.

2.1 Did any catastrophic adverse clinical events occur during the year (events or patterns of events which had significant implications for the patient and/or the service). YES / NO

If yes, details:

_____________________________________________________________

_____________________________________________________________

2.2 Were there any unplanned readmissions to intensive care during the year? YES / NO

If yes, details:

_____________________________________________________________

_____________________________________________________________

2.3 Were there any readmissions post discharge during the year? YES / NO

If yes, details:

_____________________________________________________________

_____________________________________________________________

2.4 Quality of Life (measures used to collect information and report on outcomes). Details:

_____________________________________________________________

_____________________________________________________________
2.5 Patient/family/carer satisfaction (measures used to collect information and report on outcomes).

Details:

__________________________________________________________________________

__________________________________________________________________________

2.6 Patient and transplant survival figures:

Period of analysis: _________________

<table>
<thead>
<tr>
<th>Patient</th>
<th>Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>One year from treatment</td>
<td></td>
</tr>
<tr>
<td>Five years from treatment</td>
<td></td>
</tr>
</tbody>
</table>

3. Update on status of technology

NOTE: Any potential or proposed change in the AHMAC-approved NFC service (e.g. patient pathway, patient selection criteria, model of care, etc) must be approved by the NFC Reference Group (and potentially by AHMAC) before the NFC site implements the changes. If changes to an existing AHMAC-approved NFC service are not approved, the site may not be eligible for funding for activity undertaken under those changed conditions.

3.1 An update of the status of use of the technology and associated patient outcomes in international jurisdictions.

Details:

__________________________________________________________________________

__________________________________________________________________________

3.2 Any changes in the initial estimation of demand for the service and reason for it.

Details:

__________________________________________________________________________

__________________________________________________________________________

3.3 Has there been significant modifications to the treatment being provided by the NFC if so provide evidence along with the cost implications and evidence to support these modifications.

Details:

__________________________________________________________________________

__________________________________________________________________________
4. **Cost measurement**

If there have been significant modifications to the treatment being provided by the NFC which have cost implications and an associated funding change please provide a revised NFC Costing Pro Forma (refer the NFC Guidance document – Part 3 available at [www.nfc.sa.gov.au](http://www.nfc.sa.gov.au)).

5. **Progress on the review recommendations**

Review recommendation 1 -

Comments from NFC site:

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

Review recommendation 2 -

Comments from NFC site:

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________
6. ACTIVITY PLAN FOR 20XX-XX

6.1 Anticipated demand.

Estimated number of procedures to be performed in this coming year:

__________________________

6.2 Equitable access is a foundation principle for the NFC Program. Does your service intend to undertake and activities during the year, such as outreach services, which will broaden the referral base for the service?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

6.3 What actions are planned relating to staff training, staff development and sustainability?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

6.4 Are there any expected changes to the nature of service delivery? Are you aware of emerging clinical or technology based issues which may affect the cohort for this service and impact on projected cases for the coming year?

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
You have been asked to complete this questionnaire because you /or a member of your family has recently received highly specialised treatment as part of a national initiative called the Nationally Funded Centres (NFC) Program. The NFC Program is designed to ensure that every Australian has access to certain highly specialised services, no matter where they live.

All aspects of this questionnaire will remain completely confidential and anonymous. Data collected and any written reports will not contain information that can identify you or your family in any way. The questionnaire will be sent directly to the reference group that plans and support the overall NFC Program, and not to your service provider.

We would like to hear about your experience with the NFC Program as well as any suggestions you have for improvement. While it is always rewarding to receive positive feedback, we will not be aware of areas that could be improved unless you identify them.

This questionnaire should take no more than **10-15 minutes to complete**. Most of the questions can be answered by ‘ticking a box’ but spaces are available for your specific comments. Please complete the questionnaire as thoroughly as you can. Once completed, place the questionnaire in the self-addressed pre-paid envelope provided and send it back to us as soon as possible.

Even though the questionnaire is worded from the patient’s perspective, it can be completed by you and/or members of your family, so two copies of the questionnaire have been provided. You can also access additional copies at [www.nfc.sa.gov.au](http://www.nfc.sa.gov.au).

If you would like any help with completing this questionnaire, please feel free to contact the NFC Secretariat on (08) 8226 6993 or by email at NFCsecretariat@health.sa.gov.au.

Thank you for taking the time to complete this questionnaire.

Prof Paddy Phillips  
Chair, Nationally Funded Centres Program

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NATIONALLY FUNDED CENTRES REFERENCE GROUP  
UNDER THE GOVERNANCE OF THE AUSTRALIAN HEALTH MINISTERS’ ADVISORY COUNCIL  
May 2014
Nationally Funded Centres Program

The Nationally Funded Centres Program was established in 1990 by Australian health ministers to implement a national policy for public sector provision of certain high cost and highly specialised clinical practices and technologies with limited demand; and to ensure equitable access to these practices and technologies for all Australians. Approved NFC technologies are complex, high cost technologies and are undertaken in a limited number of expert centres.

The program operates within a framework that promotes high quality outcomes. It is designed to consolidate the delivery of high cost, low volume technologies; facilitate equitable access; ensure efficient and effective delivery; and ensure maintenance of high standards of treatment and care.

This unique program is managed by a reference group with representation from each State and Territory and the Australian Government. The total program budget is jointly funded by the States and Territories on a population-share basis.

For more information on the Nationally Funded Centres Program please go to www.nfc.sa.gov.au.
We would like to begin by understanding which treatment you received and how you were referred.

1. Would you please tick the box that describes the treatment you received?

- [ ] Paediatric Liver Transplantation
- [ ] Paediatric Heart Transplantation
- [ ] Pancreas Transplantation
- [ ] Paediatric Lung and Heart/Lung Transplantation
- [ ] Surgery for Hypoplastic Left Heart Syndrome
- [ ] Islet Cell Transplantation for the treatment of severe hypoglycaemia unawareness and metabolic instability in Australians with Type-1 diabetes

2. In which state did you receive the treatment?

- [ ] New South Wales
- [ ] Queensland
- [ ] Victoria
- [ ] South Australia

3. Would you please tick the box that best describes who referred you to this Program?

- [ ] My Specialist
- [ ] My Local Hospital
- [ ] Other (Please specify) …………………………………………………………………………………………………………………

4. Where do you normally live?

- [ ] Australian Capital Territory
- [ ] New South Wales
- [ ] Northern Territory
- [ ] Queensland
- [ ] South Australia
- [ ] Tasmania
- [ ] Victoria
- [ ] Western Australia
PART A – PRIOR TO TREATMENT

We would like to understand more about the information and education you received about your treatment options.

5. Thinking about the people who cared for you in hospital before your surgery, please indicate how strongly you agree with EACH of the following statements by ticking the box that best describes your view.

<table>
<thead>
<tr>
<th>Statement</th>
<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I was adequately informed regarding the treatment I received/my child received</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. The printed information provided was useful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. The printed information provided was clear</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. The specialist team answered all my questions comprehensively:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dietician</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physiotherapist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pharmacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Speech Therapist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. During the assessment, waiting time and preparation for surgery, the Transplant Team kept me well informed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. I was well prepared for my/ my child’s surgery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. During my/ my child’s admission the members of the Transplant Team introduced themselves to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. During my hospital stay, I received an adequate explanation of the surgical procedure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. During my hospital stay, I received an adequate explanation of what would happen after the operation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
PART B – TRAVEL AND ACCOMMODATION ARRANGEMENTS

We would like to explore your views about travel and accommodation arrangements.

6. Please rate EACH of the following by ticking the box that best describes your view.

<table>
<thead>
<tr>
<th>How would you rate ....</th>
<th>EXCELLENT</th>
<th>GOOD</th>
<th>FAIR</th>
<th>POOR</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The instructions about making travel arrangements</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b. The quality of accommodation provided</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c. The proximity of the accommodation to the hospital</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d. The proximity of the accommodation to shops</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

7. Please tick the box that best describes how important EACH of the following is to you.

<table>
<thead>
<tr>
<th>How important to you is ....</th>
<th>VERY IMPORTANT</th>
<th>IMPORTANT</th>
<th>NOT VERY IMPORTANT</th>
<th>NOT IMPORTANT AT ALL</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The instructions about making travel arrangements</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b. The quality of accommodation provided</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c. The proximity of the accommodation to the hospital</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d. The proximity of the accommodation to shops</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
PART C – MEDICAL TREATMENT AND HOSPITAL STAY (POST SURGERY)

We would like to understand your experience during your hospital stay.

8. Thinking about the people who cared for you in hospital after your surgery, please indicate how strongly you agree with EACH of the following statements by ticking the box that best describes your view.

<table>
<thead>
<tr>
<th>Statement</th>
<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. After the surgery, the explanations I received in hospital about my/ my child’s treatments were clear</td>
<td></td>
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<tr>
<td>b. After the surgery, the information I received in hospital about my/ my child’s medication was clear and easy to follow</td>
<td></td>
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<tr>
<td>c. The hospital facility was well maintained</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. The medical and ward nursing staff were approachable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>e. The medical and ward nursing staff were supportive</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>f. The surgical team, including Doctors and Coordinators were approachable</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>g. The surgical team, including Doctors and Coordinators were supportive</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>h. The allied health services provided (such as physiotherapy and dietetics) were satisfactory</td>
<td></td>
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<tr>
<td>i. As I was leaving hospital, the information I received about how to care for myself/ my child at home was easy to understand</td>
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<tr>
<td>j. I was informed about follow up appointments at the hospital</td>
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</tbody>
</table>
PART D – YOUR OVERALL EXPERIENCE

9. Thinking about your overall experience, please indicate how strongly you agree with EACH of the following statements by ticking the box that best describes your view.

<table>
<thead>
<tr>
<th></th>
<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I felt confident about looking after myself/my child at home</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b. I knew who to call if things didn’t go well at home</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c. I felt confident about managing my/my child’s medications at home</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d. I found attending hospital follow ups an easy process</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>e. The quality of care I received during my hospital follow ups was very high</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<td>☐</td>
</tr>
<tr>
<td>f. My local specialist was able to provide the care I needed</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

10. Please use the space provided to make any comments

__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
PART E – FINAL SECTION

Finally, we would like to ask you some additional details that will assist us in better understanding the information you have already provided.

11. Who are you?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>☐</td>
<td>The patient</td>
</tr>
<tr>
<td>☐</td>
<td>A parent</td>
</tr>
<tr>
<td>☐</td>
<td>Whole family</td>
</tr>
<tr>
<td>☐</td>
<td>Other ________________________________</td>
</tr>
</tbody>
</table>

12. Has anyone else completed this questionnaire in relation to the same patient? YES / NO / Unknown (please circle as appropriate)

13. Would you like to discuss your experience with a NFC Reference Group member? YES / NO (please circle as appropriate)

OR

Are willing to be contacted by a NFC Reference Group member to discuss your responses further? YES / NO (please circle as appropriate)

If you answered yes to either of the above questions, please write your contact details here:
_______________________________________________________________________
_______________________________________________________________________

14. Did you experience any difficulties in filling out this form? YES / NO (please circle as appropriate)

If you answered yes to this question, in what areas did you experience difficulties?
_______________________________________________________________________
_______________________________________________________________________

Thank you for taking the time to complete this questionnaire
APPENDIX 1.3

NATIONALLY FUNDED CENTRES (NFC) PROGRAM

REVIEW CRITERIA FOR ESTABLISHED NFCS

PREAMBLE

Purpose of this information sheet:

- This information is to be used by host jurisdictions and their NFC sites to prepare a report for the reviewing body engaged by the NFC Reference Group to undertake a review of an established NFC technology.
- This criteria set out in this document and the information provided by NFC sites in accordance with this document is to be used by the independent reviewing body to guide their review of the established NFC technology.
- The elements to be reviewed for established NFCs are detailed below. The status of each of these and any associated issues should be investigated.

CRITERIA TO BE ADDRESSED

1. **Name of technology and location of NFC sites**
   
   1.1 *Specify the name of the technology.*
   
   1.2 *Specify the locations(s) delivering this NFC technology.*

2. **Nature of the technology and clinical need**

   2.1 *Access to the NFC:*
   
   - numbers and referral sources of patients;
   - clear criteria for patient selection (and, where they do not exist, a recommendation that such criteria be developed); and
   - patient demographic information.

   2.2 *Health outcomes:*
   
   - mortality and morbidity;
   - quality of life (specify instrument used for assessment of this);
   - development: physical, cognitive etc (if applicable please specify); and
   - other (if applicable please specify).

   2.3 *Model of care and service delivery:*
   
   - service scope;
   - continuum of care;
   - workforce;
   - clinical infrastructure;
   - equipment and facilities;
   - relationship with, and provision of information to, referring practitioners;
   - outreach services in other jurisdictions; and
   - current and future service gaps and constraints.
2.4 Non-inpatient services:
- local outpatient services;
- outpatient services in other jurisdictions;
- service gaps and constraints; and
- continuum of care.

2.5 Quality and safety:
- adherence to treatment protocols and care pathways;
- adherence to agreed evaluation and reporting;
- inpatient complications;
- nosocomial infection;
- unexpected re-admission or return to intensive care;
- adverse incidents;
- NFC specific adverse events; and
- patient / family / carer satisfaction.

2.6 Teaching, training and research:
- ongoing teaching and training requirements and activities; and
- research achievements.

2.7 Clinical practice:
- recent or foreseeable changes in clinical practice in the NFC, including, but not limited to, changes in the clinical indications, patient population, and technology;
- evidence of substantive changes in established NFC clinical practice; and
- development (with evidence) of existing comparative treatments that could have an impact on the NFC and / or emerging new technologies that may substitute for existing NFC clinical practice.

2.8 Service demand:
- existing demand; and
- future demand taking into account changes in clinical practice.

2.9 Cost:
- cost(s) of the NFC and comparison of costs where there is more than one site;
- cost implications of changed clinical practice;
- consideration of costing studies (national and international) and any costs which may be specific to Australia; and
- the probable effect of increasing the number of NFCs on future NFC costs.

2.10 Risk management:
- other potential risks to the viability and operations of the service, such as workforce issues, availability of clinical infrastructure at the NFC host site, and reliance on external providers;
- constraints such as transportation of organs and access for people from remote areas, or other constraints due to the geographic location of the NFC;
- strategies to mitigate these constraints and risks; and
- appropriate workforce plan within the broader health service in which the NFC is located (including workforce sustainability and succession planning) to manage the delivery of a highly specialised, high cost, low volume technology.
3. **Need for continued service concentration**

For a technology to be considered for NFC status it must require a national population base for efficient and effective service provision.

With reference to the above information, highlight factors supporting the need for continued service concentration, including but not limited to:

- the stage of development of the technology;
- health outcomes achieved to date;
- demonstrated and new evidence on the clinical and cost effectiveness of the existing technology and development of comparator treatments;
- previous and current estimates of the national and international demand for the technology;
- equity of access to the technology; and
- cost.

Issues such as optimal throughput and critical mass to determine the number of sites and the point at which additional or fewer sites might be required should also be addressed.

4. **Scope of recommendations**

4.1 **Future of NFC status:**

- The review may result in a recommendation:
  - to continue the existing activities of the NFC for a further defined period, with a further review to be conducted at the end of that period; or
  - to withdraw NFC status (which, if approved by AHMAC will come into effect effective by 30 June in the next calendar year from the date of the AHMAC approval).

4.2 **Conditions of continuation of NFC status:**

- If a decision is made to continue the existing activities of the NFC, the following outcomes may also be recommended:
  - modify the scope of services and care provided by the NFC to meet current clinical and service requirements;
  - reduce, maintain or increase the level of activity; or
  - reduce, maintain or decrease the number of NFC sites providing the service.

4.3 **Price**

- The review will recommend a price for the delivery of the technology under the NFC Program.

4.4 **Improvements**

- The review will recommend improvements to the delivery of the NFC technology identified during the course of the review.