



THE GRIFFITH AREA PALLIATIVE CARE SERVICE: A BASELINE ASSESSMENT OF ITS EVALUABILITY, SUSTAINABILITY AND GENERALISABILITY

GriffithAreaPalliativeCareServiceBaselineAssessmentGriffi

Centre for Health Service Development



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About this report

The Centre for Health Service Development has been commissioned to evaluate the *Griffith Area Palliative Care Service (GAPS)* project. This is the first of three evaluation reports. This first report is a baseline assessment of the *Griffith Area Palliative Care Service (GAPS)* project at the end of its planning phase. It includes an evaluability assessment with a view to answering the central hypothesis or key evaluation question:

That the National Palliative Care Strategy can be implemented successfully in rural Australia as assessed by improved access to care, improved quality of care, and a sustainable model of care.

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Executive Summary

This is a baseline evaluation report, marking the period up to the point where the *Griffith Area Palliative Care Service* (GAPS) project was formally launched on December 4 2001. This was the point at which the Governance Committee felt that the development phase had progressed and various structures and systems were sufficiently in place that the new arrangements were ready to publicly and confidently presented to the wider community.

The evaluation question at this point is whether the project structures and activities, the design and planning of the interventions and the information tools and systems to be used are in line with the aims of the initial proposal. The objectives of the pilot study - translating the National Palliative Care Strategy into a model of care that works for rural Australia – are ambitious because they imply that the model being tested is both sustainable in the long term and generalisable to other rural settings. The questions about whether these objectives can in fact be met, and whether the answers presented at the end of the project are likely to be clear and well supported by data, are the present focus of the evaluation and the methods that are used.

Our assessment of the project's potential for a robust evaluation process shows that the planning and design has been extremely thorough. The evidence for this conclusion is in the contribution made to the Greater Murray Area's documentation for the purpose of transparency and accountability within the wider health program structures (Area Program-level Performance Indicators and Targets). These are included as Appendix 1 and show how the planning has covered the requirements of the evaluation framework in great detail; these linkages to the health program environment are noted in Table 1.

Informed choices of data collection tools made so far should permit detailed practical testing and further development consistent with the preferred higher order framework in sub-acute and non-acute care (AN-SNAP). Recent pilot work in NSW on the use of the SNAP ambulatory care classes as a community health information tool will help inform the evaluation of the project. The Western Riverina (GAPS) experience should help in turn to accelerate the development of an information system and data collection tools that are practical to use in rural palliative care settings.

On the basis of the planning and implementation to December 2001, we conclude that there are consistent and well-documented interventions that are supported by appropriate structures and information tools (see Table 2). These should permit an evaluation of the project with implications for both models of palliative care and for mainstream information systems.

The question of sustainability has been addressed in this first report by the use of indicators developed for health promotion programs in NSW. These indicators (Appendix 1) can be used in a formative and diagnostic way to inform the management and development of the project, to measure progress at different points in time and from different viewpoints, and to provide evidence of sustainability should the interventions prove to be effective and financially viable.

We have not addressed the question of the generalisability of the model at this point, given the requirement of having sufficient data to be able to make comparisons with other rural areas. In the absence of an analysis to support conclusions at this point, it is worth noting that the project has raised considerable interest with other Areas and at conferences and professional meetings.

In summary, we believe that considerable progress has been made in a short time, that investments in personnel, expertise, service structures and management and accountability systems have been sound, and the project is well set to address its objectives.



Table 1 **Evaluation Framework for this Baseline Report**

1. Context	2. Inputs		3. Activities		4. Outcomes	5. Impacts
Description of the Palliative Care Model in the local system. Service development and capacity building Care coordination elements Service planning and delivery	Community He Griffith Base H Emergency Oncology So Other Area Se ACAT General Practitic Division of Gene	Dept ervice rvices oners & Murrumbidgee eral Practice ament Organisations gencies	System Requirements: Service standards Data collection protocols Agreements and referral protocols	Governance: Fairness Accountability Transparency 4 Information: SNAP PalCIS Integration: 2 Care planning Enhanced Primary Care	Assessment of sustainability of structures 1 Assessment of information: quality reports Project plan and role specifications, remaining boundary issues 2	Other service providers' views Consumer information Emergency Department role Changes in local response capabilities 2
Preliminary assessment of the Palliative Care Model and/or the generalisability of its elements to other rural settings • Service development and capacity building opportunities • Care coordination and intervention elements • Service planning and delivery	Staff mix OH&S concern Project Design Planning for int and sustainabil Financing the me Description of co	egration ity odel	Planning guidelines Care conference Education Consumer and family support handbook Capacity building activities ³	Indicators ² Provider and volunteer satisfaction Feedback systems: Reporting ³ Quality Review and renewal	Performance Indicators ² Service provider role specifications Provider & Patient Q&A and consumer handbook ² Wider education framework	Palliative Care providers' views: Implications for staffing & OH&S GMAHS GPs/MDGP Others Voluntary/NGO views Consumer and carers' views

¹ See Appendix 2: Assessment of sustainability using the NSW Health indicators to help with building capacity in health promotion.

² See Appendix 1: Performance indicators and targets developed by GAPS during the planning phase

^{3.} GAPS Pilot Program Coordinator's Report, August 2001 – Chapter 1 reporting; Chapters 2-4 referral, records and case conferencing; Chap 5 education p.15-6; Chap 6 evaluation summary p. 19 4. Administrative Review Council: A Guide to Standards of Conduct for Tribunal Members, September 2001.



Table 2: Summary of Findings at Baseline

Baseline Issues	Summary of Evidence	Conclusions
Evaluability Assessment On the basis of the planning and implementation we conclude that there are consistent and well-documented interventions that are supported by appropriate structures and information tools See Section 3.2 of this report for more detailed conclusions on the information issues	Data quality is already high and reports to Governance Committee are developing useful formats Performance indicators developed for GMAHS have had positive impacts SNAP reporting format is possible in current information context and the PalCIS system is compatible with minor modifications. Test of PalCIS Palm Pilot version for remote use and later down-loading shows promise	Selection of a suite of indicators to satisfy different demands of accountability, clinical utility and evaluation - current list needs slimming down Contact with PalCIS developers required for feasibility of modifications - needs detailed attention to capacity to collect all data elements and acceptability and as part of evaluation. Global report format gives adequate transparency. Interventions and target population are clearly defined at the outset Accountability will improve as indicators and information tools are refined on the basis of this report and local experience
Sustainability Indicators These show that after a period of considerable accelerated development due to the coordinator's efforts. A supportive local environment has ensured the structures are sound. Financing of the model in the longer term is the key question to be addressed in the next phase of the evaluation. See Appendix 2.	NSW Health Sustainability Indicators – GAPS given initial score of 21/28 on relevant checklist. Governance committee interviews and minutes indicate clear mechanisms for dealing with management issues as they arise	The use of the capacity building indicators subsequently with all stakeholders will be a tool to assess progress and diagnose emerging problems Governance framework is strong and investments to date have been sound
Generalisability Findings Requires data from initial project bid and other area sources - enhanced primary care data, GMAHS data - to be compared over time and with other rural areas to see similarities and differences	Few conclusions can be drawn at this point, with the model having been launched and systems put in place. Attention to the data collection issues, data quality and reporting and the financial model in the next phase of the evaluation will be crucial. See description of project and system context (Sections 1&2)	Initial indicators show strong local support. At this stage limited comparisons possible with other areas. Consumer outcomes and impacts have yet to be assessed, but these will be the key to whether other areas take up the model. Use impact and outcome measures in mid term and final reports to assess spread of model within the Greater Murray area and more broadly.



1 Introduction

The *Griffith Area Palliative Care Service* (GAPS) project has been funded as a national demonstration project and pilot study to test whether it is possible to translate the National Palliative Care Strategy into a model of care that works for rural Australia. The proposed GAPS intervention and model of care includes:

- Appointment of a Care Coordinator;
- Weekly case management review involving Palliative Care, Community Nurses, Private Nursing Agency, GP representatives, Allied Health and liaising with Emergency Dept and Pastoral Care;
- Joint intake options by case management team;
- Integrated continuous medical records across all services;
- Introduction and use of the SNAPshot palliative care information system as a patient registration and clinical information system; and
- Collection of baseline data, monthly monitoring and evaluation.

The Centre for Health Service Development has been commissioned to evaluate the *Griffith Area Palliative Care Service (GAPS)* project. This evaluation of the project involves three stages - with baseline, mid term and final reports. The focus and emphasis of each report will vary with more attention to the evaluability of the project at the start. The formal launch of the project on December 4 marks a useful end point for the baseline report. Questions of whether the model is sustainable in the longer term and the generalisability of the findings to other rural settings are discussed briefly in the baseline report and will be given more detailed attention in the later reports.

1.1 Description of Methods and Sources

The methods used in the evaluation of the project have included site visits by members of the evaluation team to conduct interviews with those involved, and telephone and paper-based survey questions and observation at the governance meetings. The assessment of the evaluability of the project includes a review of the tools for data collection and reporting, a review of documentation including minutes of meetings, the performance indicators framework from the Area Health Service and the results of various media and educational activities.

Quantitative data on clients in the project have been descriptive only up to this point, because the numbers of clients are relatively small. There have been five deaths to date and six clients in total were receiving after hours domiciliary nursing during the November reporting period. The numbers to allow more interesting analyses will build up over the life of the project.

The main issue on the quantitative side at the baseline is whether the systems for collecting data on clients and service activities will be adequate in terms of quality and whether the systems can be built into routine practice. Findings from detailed client and carer interviews are not included in the baseline report, as they have not been conducted at this point. This is because the planning and implementation issues, the structures and the interventions are the main focus at this stage.



2 The Local Context

The funding proposal for the project (titled 'Translating the National Palliative Care Strategy into a model of care that works for rural Australia – a pilot study') described the context in some detail and this need not be reproduced here. Project's objectives were outlined in terms of the national strategy³. The population covered by the project and a description of the area and its service utilisation are covered in the initial proposal⁴ and a table from the proposal is included as the baseline service description at Section 3.1 below.

2.1 History

The history of the project, including its origins in the 1998 'Sach Report' on local palliative care services, the working party in the area and the subsequent steps that were taken, is outlined in Figure 1, which was used as part of a conference presentation by local workers.

The findings of Sach Report on the situation of palliative care services in 1997-8 can be taken as a suitable "baseline" in the sense that they described the problems that subsequent working parties and the current project itself were dedicated to redress. These were:

- 1. Access for non-oncological palliative care was problematic
- 2. No operational links with community nursing
- 3. No formal volunteers network except provided by CPAS (Cancer Patients Assistance Scheme)
- 4. Inadequate data collection which failed to meet national standards

2.2 The Local Health Service System

As a sequel to the initial Sach report, additional problems were identified by the Area working party, and these also form part of the baseline description of service shortfalls before detailed planning and development work began in 2001:

- Palliative care patients were not clearly identified no actual medical record;
- Palliative patients largely concealed;
- GP involvement is variable and not coordinated. No after hours service;
- Specialist services not well coordinated;
- Specialist Palliative Care nurses overloaded with work, including after hours;
- Role of District and Private nursing not acknowledged;
- No core management, poor communication, medicine /nursing;
- No available reference material, no Q & A;
- No dedicated palliative care beds at Griffith Base Hospital; and
- Patients have no clearly defined pathway to follow after hours. As a result most end up in the Emergency Department.

A CHSD survey of the project's implementation working party in mid 2001 asked respondents what the project hoped to achieve in responding to the problems.

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NPCS Objective 2.4: Service development; Objective 3.1: Partnerships in care coordination; Objective 3.2: Partnerships in service planning and delivery.

⁴ 'Translating the National Palliative Care Strategy into a model of care that works for rural Australia – a pilot study'



The **expectations** from the working group were:

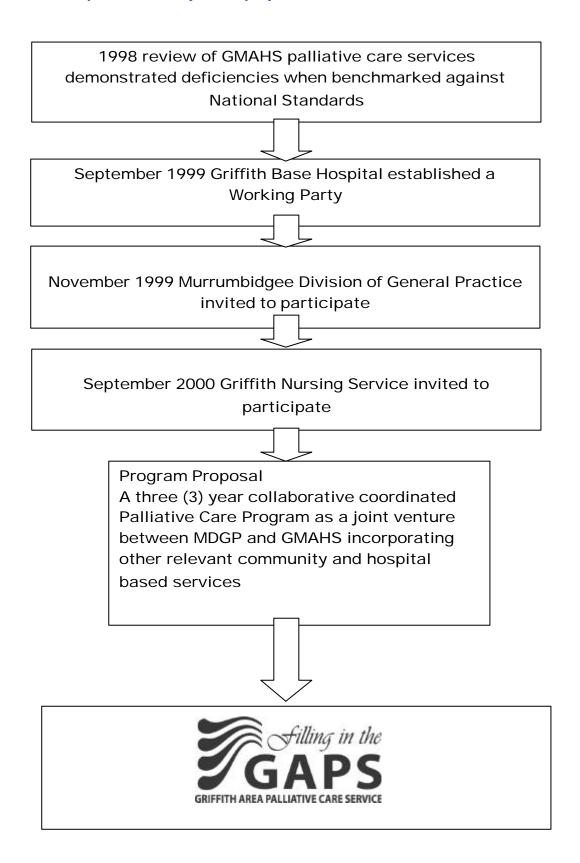
- Coordination of service, seamless service;
- Continuity of service provision;
- Reduction in inappropriate services;
- Inter-professional teamwork, GPs and other disciplines;
- Improved service to patients;
- Job satisfaction and appropriate reward;
- Time off work, i.e. shared responsibility;
- Model service, high quality; and
- Better meet community needs.

Fears included:

- Service failure;
- Loss of enthusiasm;
- Creating expectations and losing funding; and
- Missing acute disease in palliative care patients.



Figure 1: Developmental history of the project



Source: Poster presentation at NSW Palliative Care Conference, October 2001



2.3 Community Care and Support

Interviews with individuals who were not part of the health sector working party were conducted to explore what the informal care and support networks (including pastoral care and volunteers) were likely to bring to the project.

Pastoral care has evolved its own organisational forms largely outside the health service sector. There are no chaplains in the Griffith hospital, and those in the community with the interests and skills in spiritual counselling and support for the dying consult into the hospital as well as offering home support. The resulting network has developed the groundwork and acceptance of a pastoral care role among GPs, nurses and their clients. The Griffith Ministers Fraternal was already organised to cover each other when providing for the needs of the sick, the dying and the bereaved. Anglican, Roman Catholic, Uniting Church, and Salvation Army denominations have good links between themselves and with agencies in the welfare sector. This has implications for sustainability because the project can build on community structures that are already strong.

Volunteers that had been trained by Mercy Hospital in Albury, who were accredited, could be also be involved. For the project this meant the initial development work with volunteers was already under way - they only had to be offered more support and invited to the case conferences.

Community awareness of palliative care issues was also reported by informants to be high, in part because it is a small community - "everyone knows someone who has cancer". Palliative care in Griffith, as elsewhere, has historically grown up within the arena of cancer treatment. Local informants estimated that currently 95% of active palliative care patients are cancer patients. This understanding also involved some understanding of possible causes of the level of demand for palliative care - "Maybe cancer is a big problem around here because of all the chemicals used to spray the crops."

As expected in rural areas with large distances to outlying villages and properties, informants reported people moving into town to be close to services. The problems associated with this, including a shortage of town accommodation and the cost of any accommodation, suggested the need for a hospice or hospice-type arrangement as part of the project's plans.

Informants from within the project pointed to the need to visually map where services are provided over time to give a better sense of the geographic spread. This is because postcodes cover large areas and most addresses are likely to be in several main postcode areas.

2.4 Summary of context issues

The history of the service difficulties and local planning prior to the project indicate a strong base of support and fertile ground for the developments proposed.

The formal and informal care networks had responded to the difficulties of providing rural palliative care services in a planned and constructive way and the opportunities for service development afforded by the project were clear to most stakeholders at the point where more focussed efforts began.



3 Inputs into GAPS

3.1 Palliative care services

The table included in the project proposal, reproduced as Table 3 below, describes the services that existed across the area including NGO/CBO supports and general medical practitioner links at the end of 2000. These service elements represent the input of current resources into GAPS.

Table 3: Service elements in place prior to the project

Service	Location	Hours	Current Staffing
Oncology/Palliative Care Unit	Griffith Base Hospital	Mon to Fri 0900-1700	CNC in Palliative Care Registered Nurse in Palliative Care 0.4 FTE
Community Nurse	Griffith CHC	Mon to Fri 0900-1700 Sat t0 Sun 0800-1200	Community Nurse – General 2 FTE
Community Health Nurse	Hillston	Mon to Fri 0900-1700	Community Nurse – General 1 FTE
Griffith Private Nursing Agency	Griffith	Mon to Sun 24 hrs	
General Practitioners		Practice hrs plus some rostered on call for own practices	
Griffith Base Hospital	Griffith	On call	On call VMO roster for admission to wards RMOs/VMOs Emergency Department roster
Volunteer support network	Griffith & Hillston	24 hrs	Client allocation
Palliative Care team/ community nurses liase closely with GPs	Griffith & Hillston		
Cancer Patients Assistance Society			

3.2 The role of the GP in the existing system

Most community care in Griffith is provided by GPs, most of whom have a high commitment to palliative care. Medical services are provided at the surgery or at home, with specialist services available when needed. Home nursing is provided by community health and private nurses, but coordination of care has been very patchy.

Out-of-hours care has been less coordinated with some GPs attempting to cover 24 hours / 7 days week especially in the terminal cases of illness. From the GP's perspective, the job is exhausting and demanding.

After hours roster systems are currently inadequate or non-existent. Patients often end up at the Emergency Department. This entails long waits, lengthy examinations by the resident staff and often results in the patient being admitted to the ward under the care of the nominated specialist on-call.

A GP member of the project steering committee summed up the role of the GP in the existing system as follows⁵:

- Most outpatient care is provided by GPs
- The job is exhausting and demanding
- Patients often end up in the emergency department

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GP education session presentation: Palliative Care for the Western Riverina. A collaborative pilot model between the MDGP and GMAHS. September 2001.



- These are difficult patients for resident medical staff.
- Tests and procedures are often duplicated with the patient suffering poor continuity of care.

3.3 The GAPS intervention

The proposed GAPS intervention and model of care involves two elements. First, a better use of existing resources. Second, the introduction of new resources to meet identified gaps in service delivery. These two elements are integrated in GAPS to form the intervention described by the steering committee in the following terms:

- Appointment of a Care Coordinator
- Weekly case management review involving Palliative Care, Community Nurses, Private Nursing Agency, GP representatives, Allied Health and liaising with Emergency Dept and Pastoral Care
- Joint intake options by case management team
- Integrated continuous medical records across all services
- Introduction and use of the SNAPshot palliative care information system as a patient registration and clinical information system
- Collection of baseline data, monthly monitoring and evaluation.

3.4 Finance

The project's clinical activities are financed by a combination of Commonwealth and State funds including both the elements of normal funding for the Area Health Service and Medical Benefits Schedule items for GPs, including Enhanced Primary Care items.

The evaluation, the coordinator role and development costs are additional elements secured for the purposes of the pilot testing of the model. There is no secured ongoing funding to meet the costs of these elements of GAPS beyond the life of the project.

Project funds are managed through transparent systems with regular monthly reports to the Governance Committee.

The issue of donations from family and community sources has been raised with the Governance committee and a trust fund has been set up under the normal arrangements in place with the GMAHS. This will be a restricted fund used to benefit palliative care services. The register of donations may prove to be useful as an indicator of the success the project within the local community as it is described over time.

3.5 Capital

The project uses a minimal amount of additional physical capital, which includes a new computer and data collection devices. The leased vehicle is shared between the project manager and the on-call nurses.

The additional human capital, namely the project manager, who has clinical and managerial experience has enabled rapid progress to be made in the development of shared protocols and approaches which have permitted the project to go live in a short period of time following appointment. While this is a small project it is both complicated and sensitive and this appointment appears to be proving to be a very good investment in both human capital and capacity building.



4 Activities

4.1 Governance

The governance committee meets monthly and has been established with an independent chair. It is composed of each of the major stakeholders and makes decisions on policy and resource use. It receives monthly reports from the project manager and is closely involved in the detail of the project.

The governance committee is well placed and competent to ensure that the project remains on track. It gives careful attention to the areas of financial and clinical responsibility and to the quality of project reports and monitoring. This ensures that feedback to the community is maintained and that the project can be seen to act properly in addressing its task.

4.2 Clinical activity

A project working party has been responsible for developing the various clinical protocols and policies on which the project is based. The informants contacted during the evaluation stated that this committee works in harmony with the activities of the project manager/coordinator. This is a vital ingredient, which is important to the long-term success of the project. The informants stated that they are in no doubt that the success of the project to date is due to the early decision taken by the steering committee to employ a person in the coordinator role with extensive clinical experience and hence credibility within the clinical domain.

4.3 Information System

There are technical information requirements for the evaluation of the project that are in addition to the requirements for palliative care clinical monitoring and review, and also in addition to the requirements for formal program reporting under various State and Commonwealth accountability mechanisms.

The design of the project has included considerable efforts to minimise the amount of duplication and the overall burden of data collection. To this end the project has begun to use a clinical information system designed specifically for palliative care (*PalCIS*) and developed in rural Western Australia. This system in turn should have the capability of producing reports compatible with the formal requirements of NSW Health under the palliative care components of the AN-SNAP system (detail is included in the technical assessment below).

There are multiple demands on data collection that arise because the project, while having a life and context of its own which needs to be evaluated, is also part of larger systems that it is aiming to influence. These larger systems include NSW Health program performance indicators and targets as well as GP-based care planning and accountability requirements. Without strong connections to current data systems across the broader arena of health and community care, the project's long term visibility and viability would be likely to be compromised. This bears upon the questions of sustainability identified within the evaluation framework.

A clear evaluation framework is necessary for the project, but not sufficient for the longer term outcomes of the project, if the data collection burden is too great to be sustainable. Also, if the data produced within the project cannot be exported for other systems to use, the project will cause duplication, not be visible and will not be seen to be useful and accountable within the wider system frameworks.

The larger system requirements will be satisfied by the use of the SNAP data collection system, including the *SNAPshot* software and its capabilities in capturing clinical data, organising client



information in terms of episodes of care and discrete classes of patients, and reporting to other data and accountability systems.

SNAPshot can export to Home and Community Care (HACC MDS and CIARR), other Commonwealth programs (DVA, Aged Care) and provide a variety of reporting formats. However, the full *SNAPshot* system has greater capabilities and complexities than are required *only* for palliative care, making the system less than ideal for the clinical demands and rural setting of the project⁶.

In response to these concerns, the *PalCIS* system was selected by the project management for development and trial within the period of the project on the basis that:

- it is purpose-built to be clinically sensible ie designed for rural palliative care services;
- it has a portability component through a Palm Pilot format suited to remote area use and later down-loading to the client information system, and subsequently into SNAPshot;
- it has a high (although not complete) level of compatibility with the SNAPshot software; and
- it still being actively developed in WA, and so is capable of a collaborative modification to suit the purposes of the evaluation.

The key question then becomes the extent to which the *PalCIS* system is suitable for both clinical and evaluation purposes. Will it be useful for clinicians and will the development or modification costs be high? A discussion of the extent to which the role of *PalCIS* within the project meets the technical requirements of the evaluation is included below.

4.3.1 Palliative Care Data Items Required for Grouping to AN-SNAP Classes

For the purposes of this baseline report the key requirement has been to establish whether data will be collected to allow patient episodes of palliative care to be assigned to AN-SNAP classes. These data will be used in the two subsequent evaluation reports to profile client-level activity.

However, as the project is implementing data collection systems with a view that these become routine collections, data items required for other reporting also have to be considered. These include the recently implemented HACC minimum data set, the Department of Veterans' Affairs minimum data set and the ACAT AGS minimum data set. All of these various data sets are already incorporated into *SNAPshot*. The question is whether these reporting requirements can also be met with *PalCIS*. This is a question for the governance committee and project management rather than the evaluators. The role of evaluation should be to identify the key data requirements.

There are a number of technical considerations. The *SNAPshot* software system requires that variables used in class assignment be entered prior to an episode being ended. During the implementation of *SNAPshot* in inpatient and ambulatory settings, a small number of additional data items were made compulsory to assist the ongoing evaluation of the classification system. These are needed to assist in analysing the resulting data set. The same approach is therefore recommended for adoption for the current evaluation.

The palliative care classes in AN-SNAP were defined within the larger study conducted in 1996 and reported in 1997. In the NSW Health context these classes are now being used in designated palliative care units to formally report on activity.

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⁶ Comments by project coordinator, November 2001.



Table 4 below shows the clinical data items required to be collected during the project for each client to be assigned to a palliative care case type. The items needed for maintenance care are also included on the assumption that it is possible that some clients may move from palliation to maintenance and back again to palliative care. This is why the 'reason for phase end' (the same as episode end under SNAP) is included. Episode dates and the number of occasion of service provided are also required to enable episode lengths to be calculated.

Table 4 Data Items in the Ambulatory Branch of the AN-SNAP Classification

Both Case Types	Palliative Care	Maintenance
Medical Record Number	Palliative Care Phase (Stable, Unstable, Deteriorating,	Type of maintenance care (Convalescent, Respite,
Assessment Only (yes/no)	Terminal and Bereaved)	Nursing Home Type, Community maintenance
	Reason for phase end	care, Other)
Provider Type Problem Severity Score (Pain, Other Symptom, Psychological/		
(nursing, Psychosocial, Physical Therapy, Medical, Multidisciplinary)	spiritual, Family/ Carer)	
Model of Care		
Age		
Episode start RUG-ADL score	Phase Change	
Episode end RUG-ADL Score		

The Episode Level Data Items required under SNAP are available through *PalCIS* except for two important exceptions:

- Model of care
- Reason for episode end

The evaluation team is in contact with the program developers in WA and active consideration is being given to meeting the requirements for the purpose of the evaluation. At this point there appears to be no barriers, either technical or financial, to overcoming these differences between the two systems. This is because of prior contact with the developers over the SNAP requirements.

4.3.2 Reporting and Data Quality

The Global Report (for months 1 and 2 of the project) has been approved by the Governance Committee, and subject to the technical considerations raised above, is judged to be entirely adequate for the task of ensuring transparency and accountability within the project. There are no concerns about the quality, confidentiality and security of the data. The only questions are whether the formats of the reports can be made more useful for the purposes of evaluation.

The recent purchase of Palm Pilots as portable information technology using the *PalCIS* format that allows later down-loading into the patient information system has been approved by the Governance Committee. This is on the assumption that the practical and clinical usefulness of the tools to the project will be tested as part of the mid term evaluation.

4.4 Integration mechanisms

The evidence for progress on integration within the area is strong. It is attributable to the activities and strategies adopted by the project and covers:



- Case conferencing and the role of the GPs
- Patient record and how it is used
- Standardised procedures
- Hospital systems integration

The evidence up to the launch in December 2001 points to a marked acceleration of planning and service development activity in palliative care and positive add-on effects within other systems in the Area. This is outstanding given the low numbers of clients involved and the acute care systems' other salient issues. The policy framework in palliative care, set by the Commonwealth and reinforced by NSW Health and its programs, has clearly had an impact:

"The development process thus far represents a first for our region. For the first time (Area Health - GBH, Community Health), Commonwealth (Division of General Practice, GPs), Private Nursing and consumers have come together to resolve the problems collaboratively".

The products of this collaboration to date have been:

- The development of a user book for GPs;
- The establishment of a formalised and agreed notification system for GPs;
- The development of standard written forms of communication to and from GPs;
- An explanation of the project and clinical matters for patients;
- The development of resources, for self-help (with topics from funerals to constipation);
- The trialing of a format to get feedback from users;
- The translation of resources initially into Italian;
- A recognition of the growing Punjabi population and the difficulty of providing resources for them;
- The establishment of mechanisms, through the Governance committee, to ensure that communication is consistent; and
- A media plan (press clippings for the launch of the project on December 4 have been reviewed by the evaluators).

4.5 Benefits to consumers, carers and providers- education and feedback systems

Consumer and family support issues have been an important early focus of the project that have brought it considerable local and wider credibility. The project coordinator's report describes the way the educational material is being integrated with existing requirements for continuing medical education (CME) and education of all staff⁸.

As well as information and education about palliative care being made more accessible, the views of providers and volunteers, together with consumer and carer feedback systems, can be brought together by the strategies approved by the Governance Committee. As a result, provider Q&A

GP education session presentation: Palliative Care for the Western Riverina. A collaborative pilot model between the MDGP and GMAHS. 6th June 2001.

⁸ GAPS Pilot Program Coordinator's Report, August 2001 - ch1 reporting; ch2-4 referral, records and case conferencing; ch5 education p.15-6;



style information has increased, and counselling /debriefing for nurses and other staff after someone dies has been given increased attention.

"It's the on-call nurses who have to deal with dying people. Dying at home is different, more intimate than dying in a hospital. But when they go home they have no network to support them." Occupational health and safety issues arise as a result of the distance and communication problems (safety after hours, communication black spots, travelling long distances especially at night) are expected to be formally addressed in constructive ways in the course of the project. Informants interviewed by the evaluators have raised this issue as potentially one that has a role for volunteers - to accompany people in provider roles in these situations – not unlike what might happen in the course of activities in pastoral care.

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⁹ Informant interview, CHSD site visit November 2001.



5 Impacts

A series of desired impacts were identified in the evaluation framework in Table 1. A combination of internal and external evaluation methods are being used for monitoring the project and to document the intended and unintended outcomes and the impact on both palliative care services, and the wider system¹⁰. The task of the evaluation is to bring together a summary statement that includes relevant and useful data and the clearly expressed and informed views of each of the key stakeholders.

The other important precondition for measuring impacts is an information system that is capable of producing client and episode-level data for the purposes of client classification. This will go some considerable way towards answering the questions that people have of the project at this stage:

- How do we find out if we are doing a good job?
- How do you develop a project where the level of service is sustainable in the long term?
- How do we get to a system that won't rely on bringing in new staff, but rather concentrates on up-skilling existing staff?
- How do we build sustainable systems, like continuous data collection?
- How can we overcome barriers in other systems?
- How do we tap in early to the bigger strategic planning frameworks?

One informant put the project in perspective in terms of longer-term risks by painting the worst case scenario – "If everything falls over we only need to find money to maintain the on call service and the 1800 number, and maintain the data base."

5.1 Providers' views about the likely implications of the project

A series of key points were extracted from interviews with those involved in the project in August 2001:

- All providers interviewed expressed enthusiasm for the project and the opinion that it was greatly needed to coordinate the care of palliative patients in the Griffith region.
- Providers believe that there is currently poor communication between the various people involved in an individual's care. Nurses expressed the view that GPs did not consult with them and ordered unnecessary tests. GP's expressed the same view and said that nurses tended to be possessive of their patients.
- No one interviewed had a real conception of how many patients would be included in the project. All expressed the view that palliative patients would have to be clearly defined. But providers were not sure who would actually qualify for the program. For example, providers asked whether the program would be purely for cancer patients or whether it would include other terminal diseases.
- The question of whether children would be included in the program was also raised. Typical comments and questions included: Who is a palliative care patient? Is it limited to life-threatening illness with specific needs? It may be a long-term patient with special care needs, whose condition is not immediately fatal. There will be active and inactive patients.

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Perkins D. and Owen A. (2001). Impacts on mainstream services: coordinated care, mental health and palliative care. Paper delivered at the Health Services Research Conference, Wellington, NZ, December 3, 2001.



- Providers were unsure about how the project would change their work practice. Nurses expressed the view that doctors would be able to take a night off. In contrast, doctors expressed the view that it may actually increase their workload, as they may have to carry other GP's patients.
- All respondents expressed the view that the case management meetings were an essential
 part of the project and that these should be followed by informal de-briefings to cater for the
 needs for emotional support for staff undertaking what is acknowledged to be an extremely
 stressfull job.
- All expressed the view that the project would require a big culture change for GPs and that it
 would take time for everyone to learn the system and to learn to communicate effectively.
- There were some important administrative details that still need to be resolved. For example, nurses were unsure of the logistics of getting the car and phone to use when they were on call. They were also frustrated due to their lack of a computer and expressed the view that this project would be very difficult to coordinate without appropriate software to assist them.

5.2 Management issues

The governance process ensures fairness, the right to be heard, disclosure and the means of determining the use for gifts and donations. As well as the issues around accountability and transparency, informants for the evaluation raised a number of management issues that they expect will be resolved in the course of the project.

Issues around the development and continuation of the coordinator position:

- How is the project sustained beyond his role? Who can take over? How do you provide the skills (when the existing infrastructure is thin)?
- How do you improve services without creating dependency in the main change agents? How does the coordinator do himself out of a job?

Issues around maintaining improvements in service levels and quality:

- What services do we provide? (is there any duplication of services, community nursing)
- What services for Hay and Hillston (outlying communities)?
- When we extend out, will there be too much without a coordinator?
- Success maybe our downfall. If we are successful in extending to a wider area, how do we maintain this success?

Issues about the model:

- Key issues for a rural model are still to be faced, at the moment it is a community model.
- Do we use teleconferencing to further involve GPs?

Issues around the wider service system:

- Transfer of information between pastoral care and the clinicians has to be improved.
- Pastoral care providers need to know how many visits to make and believe that they can provide clinicians with greater insights into the patients' lives and needs.
- Will the multidisciplinary case conference be a place for doctors and nurses to discover other counselling resources to draw upon?



- There are minimal counselling resources in the health system vacant positions in drug/alcohol and community health.
- This is already an advantage for existing parishioners as their contact networks have been incorporated into the system. But what happens to those with no religious affiliation? There will need to be consideration of recording of religious affiliation and ensuring the response is appropriate when there is no such affiliation.

Issues around collecting outcomes measures:

- Community health data: Can you separate the palliative care workload as a component of the total? Can the same be done to separate district and private nursing hours?
- How are private nurses being included? Currently there is a proforma to put hours in and fax it through – can improvements and efficiencies be made?
- Decisions about the use of consumer outcome measures still need to be made and the approach refined to enable it to be both integrated with case conferencing and sustainable over the long term.
- The way that outcome measures are built into routine practice has been the subject of considerable attention in areas like mental health. Implications of building consumer outcome measures into routine practice in palliative care have yet to be fully explored by the project.
- Currently the performance indicators and targets for the project are extensive with no clear division of roles for who monitors what. The likely candidates for roles within this division of labour are the Area (Hospitals, Public Health Unit and Community Health), the Project, the Evaluators and the Division of General Practice. Agreement on the minimal amount of useful data that actually needs to be collected both regularly and periodically, should be reached in the light of the findings of this initial report.



6 Outcomes

The baseline report is not the place to report in detail on project outcomes but rather to report on the extent to which the mechanisms are in place to achieve and assess the desired outcomes.

While it is not possible to conclude that all problems have been solved, it is clear that the project has the following structures and processes in place:

- The structures and relationships that underpin them, are strongly linked with mainstream services, consumer and community interests.
- There are management and governance systems in place which allow management to take place and ensure that the project, and the service, are properly managed.
- The project has performance indicators and targets and there are systems to assess progress and take action if necessary.
- The project is strongly documented which is vital given the significance of the multidisciplinary collaboration at its heart.
- The project is placed within a broad education framework designed to enhance quality and develop common understandings between participants in a system of rural palliative care.

The outcomes in terms of instituting new information systems and tools will be assessed in the mid-term report. The focus in this baseline report is mainly on implementation and evaluation/data quality requirements. Informants for the evaluation did raise the issues that are likely to be needing attention in the mid term report:

- Variable levels of confidence with IT, from IT phobic to quite literate how will this develop?
- Careful that the project is not overly dependent on IT.
- Centralised medical record is an innovation and a strength, but there is some potential for problems simply because this is such a currently controversial process.
- Potential risks of the centralised medical record have to be managed (it is only as good as the person who inputs the data).
- There is a big challenge around the inclusion of paediatric patients. Initially the steering committee was not going to include them, because the approach is so different. A more active role is expected, recognising the special needs of paediatric palliative care clients and their families.

An important challenge in the next stage of the project will be to reconcile the different demands on monitoring and data collection - those of the evaluation, the project and its clinical aims and the program accountability considerations. The amalgamation of all these demands will lead to unsustainable burdens of data collection and reporting, so the task for the evaluation is to select only those items that are necessary and recommend necessary compromises.

The capacity to translate and export data items for different reporting purposes is a strength of SNAPshot, the clinical utility and portability of PalCIS is a strength, and the comprehensiveness of the Area's performance indicators and targets is a strength in terms of credibility with the wider system. It should be possible to measure outcomes in a more economical way than adding up the sum total of all possible indicators, without losing site of the different attributes of the data that have to be preserved for different purposes.



Appendix 1: Performance indicators and targets developed by GAPS during the planning phase

The following is a copy of the performance indicators and targets developed by GAPS during the planning phase. Both the program description and the associated performance indicators and targets developed by GAPS provide evidence of the high level of integration with NSW Health initiatives. This integration within the mainstream of the health system is an important source of legitimacy and credibility for the project within the Area (GMAHS) and with the State-level program managers.

Area Program Summary

Integrated Palliative Care

Program Focus:

The development of a formal service agreement between Griffith Base Hospital, Community Health, Murrumbidgee Division of GPs, Griffith Nursing Agency, Ministers Fraternal and volunteer groups to provide an integrated case management model of service for Palliative Care.

Brief Description of Proposed Program:

- Appointment of a Care Coordinator;
- A weekly case management review involving Palliative Care, Community Nurses, Private Nursing agency, GP representatives, Allied Health, and liaison with Emergency Department and Pastoral Care:
- Integrated continuous medical records across all services;
- Provision of a 24 hour access number;
- Formal GP on call roster after hours (funded by Murrumbidgee Division of GPs) includes attendance for Emergency Department presentations;
- Trained volunteer program with program coordinator;
- Formal agreement with Griffith Base Hospital VMOs for palliative care patient transfer to palliative care team Medical officer on emergency admissions;
- Education programs for Medical Officers, Registered Nurse, Emergency Department Staff, Pastoral Care and Volunteers.



Table 5 Performance indicators and targets developed by GAPS during the planning phase

Objectives	Indicators	Targets	Data Sources
Patients			
What are the characteristics of the target population and have these changed over time?	Size of the target population (ie., no. of people satisfying criteria for inclusion in the Program); Demographic characteristics of the target population; and Disease-related characteristics of the target population, including disease stage and/or severity and complications status. Implementation of SNAP data collection Defining the palliative care population	Establishing a system for accurate and timely data collection Snap data collection system to be implemented by 12/01 Increase in Non Cancer diagnosed patients Provision of statistical data	Service population audit Epidemiological data for GMAHS Census of population and housing Referral origin SNAP data
What is the level of health service utilisation by the target population?	Frequency of presentation to general practitioners; and Use of community health services. Frequency of hospitalisation Utilisation of interdisciplinary team Interdisciplinary meeting	Appropriate access Timely referral Reduction in hospital length of stay Increase in multi disciplinary care Co-ordination of care interdisciplinary team meeting to be active and evaluated by 12/01	number of GP referrals number of patients being seen by community services LOS number of different disciplines involved in care review and report of functioning of multidisciplinary team meeting
What is the level of community care service use by the target population?	For example, use of Home and Community Care services. Implementation of SNAP data collection Definition of level of community services required for target population	Appropriate access Snap data collection system to be implemented by 12/01 Snap statistical data reporting	Number of services visiting Number of after hours calls Number of after visits SNAP data
Service provision and processes			
Has the program improved coordination and continuity of care for the target population?	Extent of use of MBS items for case conferencing and care planning by General Practitioners; Strategies to support GPs' role in case conferencing and care planning in place; Extent of use of care plans/clinical pathways by service providers; Proportion of target population who have had a hospital admission that have a comprehensive discharge summary sent to their GP within one week of discharge; Strategies to ensure appropriate referral of patients to palliative care services in place; and Strategies to ensure rapid access to specialist services in place.	↑ uptake of MBS items Strategy in place by June 2001 Increase use ↑ proportion by % Strategy in place by June 2001 Strategy in place by June 2001	MAHS data Local report and evaluation number of different disciplines involved in care medical record audit Snap data reporting Number of appropriate referrals received Time between referral and first contact Time between first contact and admission Time between referral and multidisciplinary case review



Objectives	Indicators	Targets	Data Sources
			Service evaluation report provided by external consultants
To what extent are relevant service providers participating in the Program?	Extent of participation in the Program by relevant stakeholder groups; including Divisions of General Practice, hospitals, clinicians, community health and community care organisations, community organisations, Aboriginal health and medical services, consumers and carers. Extent of involvement of key stakeholders in Program management and governance.	Signed statements of commitment and involvement received by November 2000	number of different disciplines involved in care Number of services visiting or providing care Service evaluation report provided by external consultants
Resources			
How has the Program impacted on use of information management and technology?	Implementation of appropriate clinical decision support systems, clinical pathways and best-practice protocols/guidelines for use by service providers through case conferencing. Implementation of patient centred medical record Provision of 24hr telephone information line Implementation of weekly multidisciplinary meetings	Multidisciplinary case conferencing in place by 11/01 Medical record implemented by 11/01 Helpline active by 10/01 Co-ordination of care interdisciplinary team meeting to be active and evaluated by 12/01	number of patients having regular multidisciplinary case review number of disciplines using one medical record review and evaluation of case conferencing process review of policies and procedures manual uptake on availability of after hours information and assistance
To what extent has the Program changed work practices?	Evidence of personnel suitably qualified to deliver specialised components of patients' care plans. Workforce re-engineering processes to support implementation and sustainability of the Program are in place, eg., GP training, assertive follow-up.	GP training strategy in place by 10/2001 Nursing training strategy in place by 10/2001	Increase in CME points awarded to GP's Local evaluation reports on education and service delivery Service evaluation report provided by external consultants
What impact has the Program had on the demand for community health and community care services?	Availability of appropriate community-based alternatives to hospital care for the target population; and Average waiting times for access to appropriate community health and community care services.	Review and evaluation of community alternatives ↓ waiting time for services	Service evaluation report provided by external consultants Local service evaluation reports Time between referral and first contact Time between first contact and admission Snap data
Health outcomes			
What impact has the Program had on clinical outcomes for the target population?	Condition-specific indicators; Complications status Improve clinical outcomes ↓ severity/prevention	implementation of clinical indicators for benchmarking by 11/01	clinical indicators and bench marking reports
Has implementation of the Program improved the quality of life of the target population?	Extent of use of self-rated health-related quality of life measures (including functional status, mobility, role functioning); and Average self-rated health-related quality of life (eg., SF-36 and/or condition-specific measure of quality of life).	↑ use of QOL measures Improve participant QOL	To be defined ASAP



Objectives	Indicators	Targets	Data Sources
Has the Program affected the Quality of life of carers and families?	Extent of use of self-rated assessments of carer well-being; and Average self-rated carer well-being (eg., Carer Strain Index).	Measure of carer well-being in use by 2001	To be defined ASAP
Quality: Has the quality of health	care improved as a consequence of the Area Program?		
Safety	Extent of implementation of strategies to reduce crisis presentations to emergency departments, including early intervention and secondary prevention. Provision of 24hr telephone information line	↓ readmissions by % Strategy in place by 9/01 Helpline active by 10/01	Readmissions to be evaluated by multidisciplinary team, inappropriate admission to be counted as clinical indicator uptake on availability of after hours information and assistance
Effectiveness	program trial (20 patients selected) Condition-specific indicators and Implementation of a strategy to monitor key program outcomes and deliverables.	Trial to be completed by 01/02 ↑ use of best-practice guidelines implementation of clinical indicators for benchmarking by 11/01 Evaluation strategy developed by 9/01	Trial evaluation clinical indicators and bench marking reports agreed evaluation reporting system Service evaluation report provided by external consultants
Appropriateness	Percentage of hospital admissions for Program participants that adhere to best practice admission criteria. Percentage of appropriate referrals to the service	↑ appropriate admissions	admissions to be evaluated by multidisciplinary team, inappropriate admission to be counted as clinical indicator clinical indicators and bench marking reports
Consumer participation	Availability of educational material for Program participants, carers and families; Involvement of consumers in the planning, operation and governance of the Area Program; Implementation of an effective patient satisfaction measure; Evidence of effective strategies for consulting and involving people from Aboriginal and Torres Strait Islander backgrounds and linguistically and culturally diverse backgrounds in the Program.	Educational material developed by 11/2001 Appropriate level of consumer participation Satisfaction measure to be implemented_2001 Strategy in place by 2001	Local reporting systems Make up of board of governance
Efficiency	Average length of hospital stay (ALOS) for palliative care patients Cost per casemix adjusted separation in acute health services; Cost per emergency occasion of service; and Cost per primary and community-based occasion of service. Implementation of SNAP data collection Define the target palliative care population	Attain agreed ALOS Snap data collection system to be implemented by 12/01 Attain statistical data regarding specific service	GMAH's data SNAP data reporting Service evaluation report provided by external consultants



Objectives	Indicators	Targets	Data Sources
Access	Indicators of length of time spent waiting to access hospital and community-based services; and Access to services by people of culturally and linguistically diverse backgrounds.	waiting time Improved access to services	Time between referral and first contact Time between first contact and admission Clinical indicators Service evaluation report provided by external consultants
System change			
Has the Program improved the communication links between service providers in hospital, general practice and community based settings?	A process in place to ensure effective communication between service providers involved in providing care to people with the target condition Implementation of weekly multidisciplinary meetings	Strategy in place by 10/2001 Co-ordination of care interdisciplinary team meeting to be active and evaluated by 12/01	Number of appropriate referrals received Referrals source Local evaluation reports on education and service delivery Clinical indicators Complaints received Service evaluation report provided by external consultants
Has the Program improved participation in administrative and clinical decision-making by consumers, community organisations and other stakeholder groups?	A strategy is in place to facilitate receiving advice and providing feedback to community members, consumers, industry groups, health and community care service providers and other stakeholders about the Program.	Strategy in place by 2001	
Is a chronic care governance model in place to ensure the sustainability of the Program?	A structure is in place to support clinical leadership of the Program and to ensure that all key stakeholders are active participants in Program management and governance.	Structure in place by Dec 2000	Minutes from meetings of the: Palliative care service steering group Palliative care management committee Board of governance
Has dissemination of training and educational material to primary and secondary care providers improved as a consequence of the Program?	Evidence to ensure that all service providers are informed of the Program, relevant State and Commonwealth initiatives (eg., Commonwealth's Enhanced Primary Care initiative) and have access to best-practice guidelines, clinical pathways and protocols.	Information dissemination strategy developed by 10/2001	Agreed reporting structure and time frames Service evaluation report provided by external consultants
Has there been a shift in resources from the hospital to the community setting as a consequence of the Program? ⁵	Evidence of savings incurred in the hospital sector as a consequence of implementation of the Program; and A re-investment strategy has been developed to guide the transfer of savings made in the hospital sector to community-based services.	Reduction in readmissions and presentation to emergency dept Re-investment strategy developed by June 2001	GMAHs Board of governance

⁵ Advice on this matter will be sought from the Health Services in the Community Implementation Coordination Group.



Appendix 2: Assessment of sustainability using the NSW Health indicators to help with building capacity in health promotion

The indicators used to assess the sustainability of GAPS were selected after a literature review and research on factors that are important in achieving sustainability. These indicators were initially developed for assessing the sustainability of programs in health promotion¹¹

The use of individual checklists on their own has not been validated, however the report contains evidence that the reliability of the tools is adequate for formative purposes.

Checklist 4 of the indicators is designed to assess if a program is likely to be sustained. Our assessment of the GAPS project is shown in Table 6.

The answer for each item is rated on the following scale:

2 = yes, fully 0 = no

1 = yes, in part DK = don't know

Note that the term "host organisation" refers to the organisation that is seen as the one most appropriate organisation to house or support the program.

The checklist scores are based on an overall review of the project materials and the observations of the evaluation team. The checklist was scored independently by two members of the evaluation team.

There were no items on the checklist where this project had not made useful progress. Those few items where a score was less than the maximum were elements on which the project evaluation to date has limited data. These include:

- the effectiveness question (2),
- the financing/funding question for the future (4),
- the long term commitment of the organisations, which in part depends on demonstrated effectiveness (7),
- high-level organisational support and competing demands within the host organisations (9 and 10)
- the potential of the organisations for embracing innovation (11) and
- the generalisability question (14).

The overall score at the point when the program was launched was 21 out of a possible 28. The score means little in itself, but is intended as a formative guide to the project and may give useful indicators for program management.

The evaluators intend to seek feedback on this approach and use the indicators' checklist format as a survey instrument to compare different stakeholders' perceptions and how they may change over the course of the project.

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¹¹ Hawe H, King L, Noort M, Jordens C and Lloyd B. *NSW Health indicators to help with building capacity in health promotion* (January 2000) NSW Department of Health



Table 6 Sustainability Assessment

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The first set of items is about program design and implementation fact	ors.			
1 People with a stake in the program - funders, administrators, consumers/beneficiaries, other agencies –have been aware of the program and/or involved in its development	2	1	0	DK
2 The program has shown itself to be effective. Effects are visible and acknowledged	2	1	0	DK
3. The organisation which you intend to host the program in the future has been making some real or in kind support to the program in the past.	2	1	0	DK
Prospects for the program to acquire or generate some additional funds or resources for the future are good	2	1	0	DK
5. The program has involved formal and/or informal training of people whose skills and interests are retained in the program or its immediate environment.	2	1	0	DK
The next set of items is about factors within the organisational setting relate to the survival of a program	which	n are k	knowr	n to
6. The organisation that you intend to host the program in future is mature (developed, stable, resourceful). It is likely to provide a strong organisational base for the program.	2	1	0	DK
7. The mission of the program is compatible with the mission and activities of the intended host organisation	2	1	0	DK
8. Part of the program's essential 'business' is integrated into other aspects of the host organisation eg. in policies, practices, responsibilities etc. That is, the program does not simply exist as an entirely separate entity	2	1	0	DK
9. There is someone in authority or seniority, other than the director of the program itself, who is an advocate for the program at high levels in the organisation	2	1	0	DK
10. The program is well supported in the organisation. That is it is not under threat and there are few rivals in the organisation who could benefit from the closure of the program	2	1	0	DK
11. The intended host organisation has a history of innovation or developing new responses to situations in its environment	2	1	0	DK
The next set of items is about factors in the broader community environment which affect how long programs last				
12. There is a favourable external environment for the program, that is, the values and mission fit well with community opinion, and the policy environment.	2	1	0	DK
13. People in the community, or other agencies and organisations, will advocate for and maintain a demand for the existence of the program should it be threatened.	2	1	0	DK
14. Organisations that are similar to the intended host organisation have taken the step of supporting programs somewhat like your program	2	1	0	DK

Note: Shaded cell represents score for each statement

TOTAL SCORE: 21 (maximum possible is 28) = 75%