



The Griffith Area Palliative Care Service: Second Evaluation Report

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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 second of four evaluation reports. The first report described the evaluation framework and gave a baseline assessment of the project at the end of its planning phase, coinciding with its official launch. The baseline issues were whether the project could be evaluated, including how the information systems could be developed (for both ongoing management and evaluation purposes), and issues of sustainability and whether the findings could be generalised to other areas.

This second report maintains the same basic format as the baseline report, corresponding to the structure of the evaluation framework and covers the changes in the context, the inputs, the activities, the impacts and the outcomes. The new section 6 covers a detailed assessment of the capabilities of the information tools being used. It contains the evidence gathered at June 2002 (the project's mid-point) to be used in answering the 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.

Alan Owen

David Perkins

Kate Senior

David Cromwell

Kathy Eagar

Rob Gordon

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Executive Summary

This is the second report on the Griffith Area Palliative Care Service (GAPS) at the project's mid-point. It describes the new arrangements that are in place, and emerging issues (as they were at the end of June 2002) and organises the evidence available to date around the key question of whether the National Palliative Care Strategy can work in a rural area.

As the first report noted, the objectives as expressed in the original proposal - translating the National Palliative Care Strategy into a model of care that works for rural Australia – are ambitious. They imply that the model being tested is both sustainable in the long term and generalisable to other rural settings. The logic of the evaluation is to test whether improved access, improved quality and a sustainable model are the result of project activities. The evaluation also embraces the question of whether the activities would make sense if implemented elsewhere.

Our baseline assessment, that the planning and design has been efficient and extremely thorough, has been reinforced at the mid-point. We have looked at evidence from the second round of interviews with stakeholders, and from local documentation and the GAPS information system. While there are limitations in the way that information is collected and used, an active development program and policy and procedures are in place to address them.

We have not included interviews with clients at this stage; they will be analysed in the subsequent reports. So it is important to reserve judgement on improved quality, because the most important perspective on questions of quality is still missing from the evaluation. Many clinical indicators look impressive at the mid-point, including hospital stays, nursing and GP visits and average symptom scores, but we need to know more for the purposes of evaluation.

We also need to know more about the resources, logistics and practicalities of rolling out the interventions to outlying centres, as this has only just begun (as planned) from July 2002. It remains to be seen whether the GP infrastructure beyond Griffith will entertain and sustain the interventions, and how in practice the community nursing, the case conferencing and other necessary resources will be strengthened.

Increasing visibility

There is evidence that the early effort to reconcile the GAPS objectives with performance indicators for NSW Health under its Complex and Chronic Care initiative has positively influenced the visibility of the project within the wider health program structures in the Greater Murray.

Area Program-level Performance Indicators and Targets have been met in areas where they are both relevant and capable of being monitored. These remain important requirements not just for using the existing NSW funding enhancements, but as the basis for making judgements about the continuation of the model. Appendix 1 shows these indicators with comments on linkages to the health program environment.

Demonstrated progress has been made on a selection of these indicators. GAPS can demonstrate expanded service hours, increased EPC item uptake, after hours access, better records and data systems. This early and rapid progress has enhanced the project's profile within the Area, leading to its nomination for a health system quality award. This increasing visibility has led to more formal involvement of the project coordinator at Area level with increased capacity to influence the Area's palliative care planning process.

The role and importance of governance structures

The essence of the project is that care is planned and provided by a multi-disciplinary team of public and private, Commonwealth and State funded services, GPs, practice nurses and medical specialists, generic (eg, community nurses) and specialist staff (eg, palliative care and oncology nurses). Within the systems and protocols that have been developed, these staff share information, substitute for each other, share in professional education, and share insights from their work with patients. Holding these elements together through a coherent and recognised local governance structure has been a major achievement to date.

The success of this project is dependent on the logic of the pattern interventions, the effectiveness and credibility of the project activities, as well as the efficiency of the governance processes. These have to be clear to each stakeholder in the project. Each stakeholder is free to withdraw from the project thus weakening or perhaps destroying it.

While effective governance processes share general characteristics, they also have important local features and a local history. As a result they cannot be rolled out in other contexts without local analysis and local adaptation. The next stages of the project, where a broader rural model is being attempted, will test the generalisability of the model.

Access and expansion of the model to smaller communities

Small communities do not have on the ground access to specialist palliative care medical and nursing staff. Therefore the elements of the model which need to be examined and emphasised are those of the GP with generalist support from a range of nursing and other staff, volunteers and pastoral care workers with specialist advice available at distance backed up by high quality (continuing) professional education.

The interventions are in place and supported by appropriate structures and information tools (see Table 3). The associated costs and the volume of activities being developed in the project are now becoming clearer, allowing for some early projections to be made about how the model might work elsewhere and tentative conclusions to be drawn about how it might be sustained.

There is good evidence at the mid-point that the development of systems and procedures provides a solid foundation to expand the model to outlying rural centres, namely Coleambally, Darlington Point, Hay and Hillston. The cautious but active promotion of the rural model has taken into account the numbers of potential patients, the level of nursing and GP coverage, as well as the requirements for on-call coverage, case conferencing, data collection, equipment and consumables.

Data improvements

The initial conclusions in the Baseline Report, that the project is developing an information system and data collection tools that are practical to use in a clinical sense in rural palliative care settings, are still valid. As expected, the numbers in the project remain low (although more than many stakeholders initially expected), and that limits the amount of analysis that is possible. Nevertheless, the patient held record, the Palm Pilot format, and the centrally held (PalCIS) data give useful feedback to clinicians and some descriptions of the project's activity for management purposes. How useful the information becomes over time depends in large part on how the data are collected and subsequently organised and fed back to all the interested stakeholders.

The data collected under the PalCIS system are consistent with the preferred higher order framework in NSW for sub-acute and non-acute care (AN-SNAP), however the consistency of data collection is still an issue. The routine collection of data that allow patients to be assigned an episode of care at each change of phase, is the key activity that should be encouraged. These limitations at this time are not surprising as an ambulatory AN-SNAP collection has not yet been put in place for routine use in community health settings. As a result, meaningful comparisons can only be made at this point with the AN-SNAP research data. When AN-SNAP is being routinely used, comparisons of GAPS and other centres in the Area will be possible on a routine basis. In the interim, some data analyses can be carried out by the evaluators (CHSD), with the assumption being that these analyses might be carried out in the local setting or at the Area level, with a bit of development work and assistance from the evaluators and the PalCIS developers.

A technical assessment of the information system components (ie, mainly how PalCIS was being used in June 2002) is included in this report at Section 6, along with specific recommendations. While the data collection burden has been well managed and the Palm Pilot format has proved popular and useful mainly for the nursing clinicians, its usefulness beyond the clinical domain remains unproven. This section of the report recommends improvements to how the clinical data might be used for the project's management purposes and how more meaningful reports can be produced for stakeholders. The recommendations include emphasising the importance of periodic reassessment of patients to more accurately record changes of phase, and capturing hospital inpatient data and Emergency Department presentations.

The necessary software solutions (including the recommended improvements such as exporting to Excel) are the responsibility of the PalCIS developers, not the project itself. In the interim, the project needs the capability for graphing nursing hours and GP visits and for better reporting longitudinal data by the phase of care. PalCIS is not currently used to full effect in reporting by phase, and the reports mainly deal with one variable at a time. There are implications for both clinical information in models of palliative care and for mainstream information systems.

Long term viability

The question of sustainability was addressed in the first report by the use of indicators developed for health promotion programs in NSW. These indicators (Appendix 2) are used again for their formative and diagnostic value in guiding the management and development of the project. No indicators showed decline, and three indicators about the host organisations (building into organisations' plans; high level commitment; interest in promoting like programs) have shown identifiable improvement in the period between reports.

However, the main indicator of sustainability, given the early evidence that the interventions are perceived by providers to be effective, is whether the coordination processes established are financially viable. At the project's mid point (July 2001 to June 2002) it is clear that GP case conferencing activity has increased (from 0 to 58 EPC items in the palliative care population) and that this level of GP activity can be sustained and expanded to include assessment and care plans. Within mainstream arrangements, the investment in increased activity to June 2002 in the on-call coverage (\$22,500) and equipment costs (\$2,500) is modest and is justified by the increased activities.

Covering the costs of the coordination functions (the coordinator position, the secretarial role for EPC items, management and governance arrangements) beyond the project implementation phase remains the outstanding question for the project management and Board of Governance. They will inevitably have to deal with reconciling different stakeholder interests to bring about either a means of continuing current arrangements, or changes of roles.

The project is now in a position to do some cost estimates based on the actual workings of the service model and its related interventions. One obvious scenario is bringing the GP EPC

payments from “off-budget” to on-budget and using them as part of a pool of funds that would be used to cover both the service enhancements and the service planning role.

The modeling of different scenarios will need to be preceded by the improvements in the data systems and skilled planning and negotiation between the key stakeholders. The purpose of some cost modeling in the next stage is to see where there are continuing sources of funds that might be better utilised in the project. EPC items for care planning, assessments and mental health have yet to be accessed. It is unlikely that the GPs will want to expand this activity without assistance, given the other demands on their time, particularly in the smaller communities. They may well participate in such arrangements if the administrative components can be undertaken by project or Division staff and appropriate payments made as allowed for in the design of the EPC items.

The coordinator has played a vital role in the detailed design of the project, the negotiation of protocols, and the day to day management of the project – particularly the case conference which lies at the core of the intervention. The continuing requirement for coordination may vary from that required in the start up phase, and will depend on how the extended model in outlying communities evolves. It is still too early to tell.

The balance of the coordinator's time and attention has now switched to rolling out the project in the smaller communities within the Area. The costs involved and the ways around the inevitable difficulties of this roll-out will be one focus of the third evaluation report. Careful consideration of the costs of the extended model is very important in answering the question of whether the palliative care strategy can work in rural areas.

Quality of care

The project continues to measure improvements on selected performance indicators. Notes are attached in a 'comments' column in the table of indicators (Appendix 1). This column notes where information is available, where it is still to be collected and where it is unlikely that the recommended information will be meaningful. The early indications are that there have been increases in the number of community nursing hours in palliative care, reductions in acute bed-days for patients on the program, increased numbers of deaths at home, increased involvement in multi-disciplinary case conferences and more direct involvement of voluntary agencies and pastoral care. A brief discussion of how the framework of indicators might be made more useful is included in the Appendix.

What we do not know as yet are the relationships between increased hours and patient indicators (symptom scores, phase of care), and hospital bed-days and Emergency Department presentations. There is also room to improve what is known about the link between the place of death and patients' preferences, and how patients and carers can be more formally built into the processes involved in creating the plan of care.

Better indicators of quality are relevant to the generalisability of the model at this point, since there are now sufficient data to begin to make more meaningful comparisons over time and with other rural areas. The proposed record audit inside the Griffith Base Hospital and the comparisons with GMAHS data on activity in other localities will highlight what progress has been made on reducing the inappropriate use of hospital resources.

The most important piece of evidence about whether the project has changed the experience of patients, and in what direction, is to be gained from the interviews with contemporary patients and carers and the recently bereaved. The framework for these interviews is outlined at the end of section 5.

Education and training

The project makes use of existing educational resources for GPs, nursing and pastoral care material, and can access these via video, satellite TV, CD Rom and visiting speakers. It is also developing its own educational material and patient information brochures.

All educational material is made available to nursing homes and to the Griffith-based private nursing agency. The project steering group has acknowledged that there are still barriers to overcome in outreach to nursing homes.

The project continues to raise considerable interest with invited talks and papers in other Areas and at conferences and professional meetings. The list of contributions by a range of those project participants involved, is growing. All participants report an increase in their knowledge and skills, and confidence in the value of the program, as a result of the activity to June 2002.

Implications of progress to date

This is an evaluation of a project that has a high degree of policy relevance. It is likely that decisions will be made and actions taken at various levels before practitioners and researchers have final results and clear ideas of how the model will and will not work in practice in different settings.

In this study there is evidence that the case conferencing EPC items are useful, but the project is yet to address the care planning, assessment and mental health items. These seem more difficult to organise (in terms of the paperwork and available specialists) and a strategy to use them was being developed at the time this report was prepared. The case conferencing items are currently "off-budget" as far as the resources to the project are concerned, yet they are administered through the project and they do provide participating GPs with some compensation for their involvement in multi-disciplinary case conferences. How useful they will be beyond this role is yet to be determined.

In summary, progress in changing and refocussing local activities (seen in terms of the practical implementation of the objectives and the interventions) has been achieved with a high level of consensus. The development of the model of care has been accelerating over the eight months since the formal launch in October 2001. The project is well equipped, now that it has now reached a critical period, to evolve a practical model for outlying areas. Data quality and its usefulness for management and evaluation has been improving to a point where research can now highlight important findings and give direction. The relatively modest investments in equipment, service delivery improvements, structures and management and accountability systems have been sound, and in terms of measurement against the baseline list of State-level performance indicators, the project is already meeting its objectives. Questions of the generalisability and sustainability of the model remain unanswered at the time of writing this second report.

Table 1 Evaluation Framework (Second Report)

1. Context	2. Inputs	3. Activities	4. Outcomes	5. Impacts	
Description of the Palliative Care Model in the local system. <ul style="list-style-type: none"> • Service development and capacity building • Care coordination elements • Service planning and delivery 	Greater Murray Area Health Service: <ul style="list-style-type: none"> Community Health Griffith Base Hospital • Emergency Dept • Oncology Service Other Area Services • ACAT 	System Requirements: <ul style="list-style-type: none"> • Service standards • Data collection protocols³ • Agreements and referral protocols 	Governance: <ul style="list-style-type: none"> Fairness Accountability Transparency⁴ 	Assessment of sustainability of structures ¹ Assessment of information: <ul style="list-style-type: none"> 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
	General Practitioners & Murrumbidgee Division of General Practice <ul style="list-style-type: none"> • Non-Government Organisations • Voluntary Agencies • Carers and Consumers 		Information ² : <ul style="list-style-type: none"> SNAP PaCIS 		
Preliminary assessment of the Palliative Care Model and/or the generalisability of its elements to other rural settings <ul style="list-style-type: none"> • Service development and capacity building opportunities • Care coordination and intervention elements • Service planning and delivery 	Staff mix <ul style="list-style-type: none"> OH&S concerns 	Planning guidelines <ul style="list-style-type: none"> • Care conference • Education 	Indicators ³ Provider and volunteer satisfaction ⁴ Feedback systems: <ul style="list-style-type: none"> • Reporting³ • 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 ⁵
	Project Design <ul style="list-style-type: none"> Planning for integration and sustainability 				
	Financing the model <ul style="list-style-type: none"> Description of cost centres 				
	Capital requirements Physical Human				

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

2 See Appendix 1: Assessment against Performance indicators and targets developed by GAPS during the planning phase, as well as comments.

3 GAPS Pilot Program Coordinator's Reports, Jan-June 2002 – plus various ad hoc reports.

4 Interviews carried out in October 2001 and June 2002

5 Interviews with consumers and carers will be included in the Final Report.

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1 Introduction

The *Griffith Area Palliative Care Service* (GAPS) project has been jointly funded (Commonwealth and State/Area funds) 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 GAPS intervention and model of care is described in Section 1.1, and more detailed descriptions of the interventions and impacts are covered in Sections 2 and 3 and in Appendix 1 which covers the initial performance indicators and comments on progress to June 2002.

1.1 What is the GAPS model?

The system of rural palliative care being developed in stages in the Western Riverina is a service model that went 'live' on October 1, 2001. Key objectives and elements are shown in Table 2. The model is evolving progressively as it is attempting to address more complex problems, due mainly to population density and distance, shortages of specialised staff and GP coverage and support. Many of the problems being addressed are not specific to palliative care and may be exacerbated in rural settings, for example, recruitment and retention of staff, data collection and information management, multi-disciplinary practice and teamwork, and integrating roles for carers, pastoral care and voluntary support.

Table 2 *Program objectives and elements*

The five objectives identified at the baseline	The model has the following elements
1. To provide a high quality and responsive service to patients and carers.	<ul style="list-style-type: none"> ▪ Governance committee ▪ Multi-disciplinary planning group ▪ Additional resources for evaluation
2. To ensure that appropriate care and expertise are available when needed.	<ul style="list-style-type: none"> ▪ Nurse project manager ▪ Expanded multi-disciplinary professional education
3. To prevent inappropriate use of services such as use of Accident and Emergency or hospital in-patient services when better alternatives are available.	<ul style="list-style-type: none"> ▪ Negotiated patient protocols ▪ Out of hours nursing and medical cover arrangements
4. To use active multi-disciplinary care planning to permit coordinated services, anticipate patient problems and respond to patient preferences such as place of care.	<ul style="list-style-type: none"> ▪ Case conference/care planning system ▪ Patient held record ▪ Data collection system (PalCIS) ▪ Information system
5. To make this service available to all who need it within the community.	<ul style="list-style-type: none"> ▪ 1800 telephone number advertised (TV) to the community

At June 2002 there were still practical service limitations to overcome which included a shortage of psychosocial counselling resources, and revisiting the distance criterion for home visits out of hours due to staff coverage and health and safety considerations. These are important in the context of moving to a rural model suitable and sustainable in outlying areas.

Steps to be taken to progressively overcome these limitations have been agreed by the Steering Committee and Board of Governance and are discussed in Sections 2.3 to 2.5 below.

1.2 Evaluation methods and sources

The evaluation of the project involves ongoing assessment and recommendations for further development across a series of reports. The focus and emphasis of each report will vary as the project develops and data improves. Questions of whether the model is sustainable in the longer term and the generalisability of the findings to other rural settings are discussed in each report and will be given detailed attention in the final report.

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, analysis of data and documentation, and direct observation through attendance and teleconference at the various meetings.

Data have accumulated within the information system, including PaICIS and other paper-based elements, to a point where information has been collected on 54 patients (to June 2002). This report uses this information as the basis for the description of the activity to date, and as a way of making some comparisons between GAPS and other data sources. A record audit in the hospital will select a sample to match those in the program. Appendix 3 shows the list of diagnoses to be used as a starting point for matching patients to be included in the record audit. To allow some inferences to be drawn from comparisons with other locations in GMAHS and/or with similar-sized services in other Areas, planning data from the Area will also be used.

This current report mainly uses the accumulated interview material from the site visits and a number of the available quantitative measures to draw early conclusions about the current strengths and weaknesses, and on this basis make inferences about the likely generalisability and sustainability of the GAPS approach. Interviews with the clients and carers are not reported at this stage.

The research agenda at this point consists of:

- A record audit in Griffith Base Hospital (GBH) based on matching the project patients with controls (ideally the sample will be based on a 1:4 ratio of patients to controls) to confirm claims that ED pathways for palliative care patients have improved. The key variable of interest is the number of ED admissions.
- The GMAHS Director of Health Service Development has offered access to data for making comparisons between GAPS and other services across the Area. Dedicated resources to support this work are part of the current funding arrangements. Comparisons will be made with other similar sized centres through the NSW DOHRS or SNAP collections. These data can be used to confirm in more detail the claims that the GAPS model is offering better access and extended coverage to that available in other parts of the Area and elsewhere in rural NSW.
- Data on GP EPC use through the Division will include evidence of the GAPS role in increasing EPC uptake, based on comparisons with other rural Divisions. This can be used a basis for projections of the revenue base from MBS billing under the enhanced primary care items. The data will help assess the potential of sustaining key elements of the coordination role, especially in support of the processes and procedures associated with case conferencing.
- Including the clients of the GAPS program or their families in our interviews.

The main issue for the evaluation at this point is whether the systems (1800-number, on-call rosters, data, client records and case conferencing) are being built into routine practice and being extended beyond Griffith. Findings from interviews and the project's information system are included in this report, and these are compared with the data available at the baseline.

2 Changes in the Local Context

The original proposal (titled 'Translating the National Palliative Care Strategy into a model of care that works for rural Australia – a pilot study'⁶) described the context in some detail, with objectives based on the national strategy⁷. The population covered by the project and a description of the area and its service utilisation are covered in the initial proposal. Table 5 from the proposal with the changes at June 2002 is included at Section 2.4 below.

2.1 Background to the service changes

The history of the project, including its origins in the 1998 'Sach Report' on local palliative care services⁸, provided a foundation consistent with the Standards for Palliative Care Provision developed by Palliative Care Australia⁹. The agenda of the working party in the Area and the subsequent steps that were taken, is outlined in the Baseline Report.

The problems that subsequent working parties and the GAPS project were dedicated to redress 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 Society); and
4. Inadequate data collection which failed to meet national standards.

As a sequel to the findings and recommended model in the Sach report, additional problems were identified by the Area working party, and these formed the description of service shortfalls before detailed planning and development work began in 2001.

The changes at mid 2002 are described in the tables that follow.

Table 3 GAPS Changes from the Baseline to June 2002

Baseline	June 2002
Palliative care patients were not clearly identified - no actual medical record that identified them	Patient held record in use, staff training and flags available in hospital records. Palliative care patients identified much earlier.
Palliative patients largely concealed	Clearer distinction of palliative and oncology patients, palliative care service patients known to the system.
GP involvement is variable and not coordinated. No after hours service	Clinicians discuss patients at weekly M/D meeting. On-call service and after-hours coverage in place. GPs cover for each other, and 3 nursing service types are included. Separate Palm Pilot for after hours captures call-outs in database.
Specialist services not well coordinated	Model of shared care and consultation by specialists in place - still issues to resolve with shared care models, visiting (fly-in) services, and area-wide models.
Specialist Oncology nurses overloaded	Load now spread through on-call roster and consultant model, with extension

⁶ Murrumbidgee Division of General Practice: Translating the National Palliative Care Strategy into a model of care that works for rural Australia – a pilot study, March 2001.

⁷ Department of Health and Aged Care. *National Palliative Care Strategy*, September 2000. Objective 2.4: Service development; Objective 3.1: Partnerships in care coordination; Objective 3.2: Partnerships in service planning and delivery.

⁸ Greater Murray Health Service. *Palliative Care Framework*, September 1998.

⁹ Palliative Care Australia, *Standards for Palliative Care Provision* (2nd edition, June 1998).

Baseline	June 2002
with work, including after hours	begun to outlying towns.
Role of Community and Private Nursing not acknowledged	Generalist nursing a key part of the model and palliative care. skills being developed in both public and private agencies
No core management, poor communication medicine /nursing	Coordinator role developed, with protocols and procedures for handling information and assigning responsibilities
No available reference material, no Q & A	Relevant clinical education material accumulated and used, and community information now developed, patient and carer information booklets available
No dedicated palliative care beds at Griffith Base Hospital	No dedicated beds, but patients are identified on admission as part of the policies and procedures of the project.
Patients had no clearly defined pathway to follow after hours. As a result most ended up in the Emergency Department.	After-hours roster in place, with dedicated medicines box, plus hospital CNC and RN in ED involved in project activities.

The changes to the model of care that are promoted through the project are highlighting the pros and cons of other formal and informal models, both locally and in the wider the Area. These matters are not clear cut as there are many variations within and between models that have to tailored to local circumstances. For example there are many variations of shared care and collaborative care with GPs, which are well documented in the primary mental health care area¹⁰.

2.2 Changes in the expectations of key stakeholders

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. Interviews one year later show how those expectations and fears have changed as a result of the activity to date.

Table 4 Changes in stakeholders' expectations from 2001 - 2002

Working Party expectations and fears in 2001	Changes in 2002
Coordination of service, seamless service	There is now a flag on the medical record for palliative care patients, patients hold records, consolidated use of assessment data, weekly m/d case conference.
Continuity of service provision	GP and nursing rosters, 24hr on-call, policies and procedures in place.
Reduction in inappropriate services	Fewer presentations to ED and patients being admitted less. Now getting the more difficult and expensive clients admitted (those requiring 24-hour nursing).
Inter-professional teamwork, GPs and other disciplines	GPs, three nursing groups, hospital and pastoral care all at case conference, sharing of education opportunities and specialist skills.
Improved service to patients	Improvements in access, educational materials produced Patient/family interviews still to be reported.
Job satisfaction and appropriate reward	Interviewees report consistently on improvements and observations of meetings indicate high level of enthusiasm remain.
Support to emotional needs of staff	Staff not working in isolation, supervisory and support systems in operation.
Time off work, i.e. shared responsibility	Policies and procedures, including the roster and arrangements for after-hours equipment and data collection protocols mean that responsibilities are acknowledged and shared.
Model service, high quality	Interest from outside the project has increased. Area and Commonwealth requests for information, and feedback from conferences show promise.

¹⁰ See the descriptions in the Primary Mental Health Care Australian Resource Centre, parc@flinders.edu.au

Working Party expectations and fears in 2001	Changes in 2002
Better meet community needs	Indicators and targets show some significant progress in areas of sharing responsibilities and after-hours coverage - see Appendix 1 and comments included in the indicators summary table.
Service failure	No evidence at this point of signs of failure, and indicators of local capacities have improved – see Appendix 2.
Loss of enthusiasm	Evidence from testimonials and donations indicates an increase in the local community awareness of the project.
Creating expectations and losing funding	There is confidence about the viability in the Griffith area, but caution continues about how the roll-out to outer areas will proceed. No evidence of threats to funding.
Missing acute disease in palliative care patients.	Case conferencing format, regular symptom assessment and use of specialist consultations were reported to have improved quality. Formal arrangements with specialist units are still in negotiation ¹¹ .

The agreements reached on many important issues in the first year of the project have met and in many cases exceeded the expectations of the stakeholders. The extension of the model to outlying communities will test the reliability and generalisability of these agreements and procedures. Dealing flexibly with the different conditions in different towns, and adapting what has been learned to accommodate the expansion of the model, will be the significant challenge for the management of the project in the next stage.

2.3 Community Care and Support

The interviews indicated that the more coherent focus of GAPS, by mid 2002, has helped the range of local agencies by increasing the total amount of specialised skills and information available in the rural setting.

Critical for (our service) is providing trust and increased confidence. It provides an opportunity for professional development, increasing my knowledge and skills. Also the same goes for my staff. (2002)

There were no reports of unintended impacts or disagreements about cost shifting. The ongoing development of the policies and procedures, in guiding the activities of the project, were expected to sort out various problems as they arose. There are many difficult problems in this type of care, especially related to the patient's and carers' spiritual needs and how these are best met in bereavement.

We need formal bereavement care. Sometimes it is unclear whether this should be done by the nurse attending to the family or by a minister providing pastoral care. This should be up to the families. Nurses will get an indication from the families when they are no longer needed. (2001)

Subsequent interviews with patients and carers as well as volunteers, will assist our understanding of unintended impacts. The view in 2001 was that there was still a considerable way to go in strengthening the role of volunteers, in particular the need for a paid volunteer coordinator.

We need more support for carers - volunteers could be involved more. There are currently 18 volunteers but they are not always available. The next training programs for volunteers will have screening to ensure that they will be available for the next twelve months.

¹¹ The Sinclair Report number 2 for NSW Health recommends extending the 'hub and spoke' arrangements between hospitals in rural NSW to better manage specialist shortages.

Otherwise they are a waste of resources. There are some people who always come to training, but are never available to actually do anything (2001).

A contributing factor to the lack of support for volunteers is the major shortfall in psychosocial counselling services. The core elements of the GAPS model are strong but the lack of psychosocial services is a weakness, leaving more work for pastoral care than is reasonable to expect, given the relative availability of resources. As the model extends into outer rural areas and comes to terms with large distances to outlying villages and properties, this problem is expected to get worse.

The absence of psychology and counselling means there is still room for a social worker and perhaps a welfare capacity to be built in. A trained psychologist/counsellor was sponsored for palliative training last year and then retired. (2002)

There was some interest in how the Commonwealth's Better Mental Health Outcomes Program¹² will make an impact on this issue in future. The likely outcome of losing scarce and expensively trained staff from Community Health to GP Divisions was raised as a threat that might well need to be managed through the auspices of the project¹³. These problems are not uniquely associated with the GAPS arrangements and are common to rural areas where they have potential to amplify the existing recruitment and retention difficulties for public sector services. It was pointed out that the governance arrangements, by including Area, community health, hospital, private nursing and GP interests are well suited to managing these structural difficulties.

2.4 Palliative care services

It was not that there were inadequate services in the past or that the levels of expertise were not high. It was more that there were role confusions and a lack of an integrated approach. The changes from past practices to how the model operates in June 2002 are practical, have divided the roles in agreed ways, and improved communication.

I have been doing palliative care in the community for 28 years under a two tier nursing system composed of personal care and other nursing. Currently there is a great deal of confusion between services, there are different sets of notes and different opinions. This makes it difficult for both patient and staff. Communication isn't easy. (2001)

It also puts me in touch with the district nurses and the practice nurse at the doctor's surgery – for example in wound care - because we all do things a little differently, the face to face contact enables us to work together more efficiently. (2002)

The interviews and planning documents provided some evidence that the model has developed in ways that are different to other localities. This still needs to be confirmed with more up to date information from the Area.

The participants interviewed have pointed to two dimensions of change as a result of the new model – the consolidation of a generalist base and the collective approach to client care where responsibilities are clearly shared and care is planned with a broader view of need.

¹² This initiative was announced in the Federal Budget Papers 2001/2002. The implementation framework for the Better Outcomes in Mental Health Care is being developed by the Committee for Incentives for Mental Health. The development of the training package and the roll out of the training will be coordinated by the Australian Divisions of General Practice, with assistance from the State Based Organisations.

¹³ There is a perception that Divisions may be able to offer better terms and conditions than State funded community health services.

In the past the community nurses had the responsibility for the care of their individual patient. They were their individual patients. Now ownership will be the responsibility of the service, not the person caring for them. (2001)

Table 5 below shows the changes to the input of resources into GAPS from the end of 2000 to June 2002.

Table 5 Service elements in place prior to the project and at June 2002

Service (2000)	Location	Coverage (2000)	Staffing (2000)	June 2002
Oncology/Palliative Care Unit	Griffith Base Hospital	Mon to Fri 0900-1700	CNC in Palliative Care Registered Nurse in Palliative Care 0.4 FTE	CNC on roster, role in education, research and clinical input built into p&p manual and training (.4+.4 RN also) 0.8 FTE
Community Nurse	Griffith CHC	Mon to Fri 0900-1700 Sat to Sun 0800-1200	Community Nurse – General 2.4 FTE includes weekends	Extra resources for on-call roster, extra training, providing support to generalists
Community Nurse	Hillston	Mon to Fri 0900-1700	Community Nurse – General 1 FTE	Negotiations to cover costs of on-call (average of 32 hours per month used now)
Griffith Private Nursing Agency	Griffith	Mon to Sun 24 hrs	No formal arrangements around palliative care	On rosters, at case conferences, on Governance Committee
General Practitioners	Griffith Leeton Colleambally Hay Hillston	Practice hrs plus some rostered on call for own practices	No formal arrangements around palliative care	GPs rostered on call. (average 82 visits per month, 825 total) Some nursing substitution. Service starting in Leeton and Coleambally.
Griffith Base Hospital	Griffith	On call	VMO roster for admission to wards. RMOs/VMOs ED roster	GP palliative care roster, ED RN (.4) coverage, policy has roles delineated and procedure manual in place
Pastoral care network	Griffith and other localities	Across area through Ministers Fraternal and Multicultural Council	No formal arrangements re palliative care except through chaplain role in hospital	Attendance at case conferences and some mention in policies and procedures
Volunteer support network	Griffith & Hillston	24 hrs	Client allocation by volunteers. No paid coordinator	Roles described in policy and procedure manual
Hospital Palliative Care team/ community nurses liase closely with GPs	Griffith & Hillston	Ad hoc basis	No shared assessments with other nurses or GPs	Attendance at weekly M/D case conferences for approx. 20 patients. Roles clear in policy and procedure manual
Cancer Patients Assistance Society	Area-wide	Ad hoc basis	Through oncology unit	Role described in policy and procedure manual

The configuration of service elements will expand and may undergo changes as the project expands to outlying communities. The CNC coverage will expand and this resource is already spread thinly in covering existing demands inside and outside hospital. Hand-over issues for after hours and information-sharing at case conferences will become more complicated for all stakeholders. The project appears well-placed to negotiate solutions to these pressures.

2.5 The role of the GP in the system

Out-of-hours care has been coordinated with a roster and nurse triaging of patients has reduced the number of GP visits that are necessary. GPs in Griffith no longer attempt to cover 24 hours / 7 days a week in the terminal cases of illness, and can do other things with their time.

From the GP's perspective, the job was exhausting and demanding and this is no longer reported to be the case.

There are a lot of sick and dying people. You [the GP] get exhausted and it wears out doctors. (2001)

The after hours roster systems are working and allow GPs to undertake other hospital work such as medical and surgical procedures instead of after-hours home visits which are now covered by the work of the nurses. Patients are reported to be presenting less often at the Emergency Department and this is expected to be confirmed by data collected through a hospital record audit.

They tended to treat people when treatment wouldn't make any difference. It is cruel to subject people to unnecessary treatment. (2001)

The role of the GP in the system before GAPS¹⁴ can be compared with the findings from interviews, observations and the information system at June 2002.

Table 6 Changes to the GP role at June 2002

Reported role in September 2001	June 2002
Most outpatient care is provided by GPs	Multi-disciplinary approach and closer liaison with nursing staff
The job is exhausting and demanding	Shared responsibilities said to help; substitution of other hospital or private surgery activity for patient call-outs improves quality of GP work
Patients often end up in the emergency department	Suggestion of fewer ED admissions (this is yet to be confirmed)
These are difficult patients for resident medical staff.	Increased education, GP roster and policies and procedures said to help significantly.
Tests and procedures are often duplicated with the patient suffering poor continuity of care.	Shared assessment information, symptom monitoring, flags on admission and common records said to help

While the changes to how the GPs work are an important part of the changed arrangements, it must be noted that they are only one part of the total picture, and by no means should it be assumed they are in the driving seat. GAPS is a shared and multi-disciplinary model with a strong generalist base (in general practice and nursing) and important specialist inputs of palliative care and oncology nursing, visiting palliative care and oncology medical specialists and pastoral care.

The project has been designed to bring these different elements together in support of GPs because of the continuing shortage of GPs and other specialist expertise in rural areas. The role of the local Division has been very important, both in providing organised GP input through

¹⁴ GP education session presentation: Palliative Care for the Western Riverina. A collaborative pilot model between the MDGP and GMAHS. September 2001.

participating members, and by sharing administrative burdens in ways that make the project very 'GP-friendly'.

The Admin Assistant works 16 hours per week through MDGP – and works all day Friday on the EPC items at the community health offices ... the copy of the PaLCIS case conference records can verify claims. (2002)

2.6 The GAPS interventions and activities – assessment of model at June 2002

The GAPS intervention and model of care involves essentially two elements; systems re-engineering to gain a better use of existing resources and the introduction of new resources to meet identified deficiencies in service delivery. These two elements are integrated in GAPS to form the objectives, interventions and elements of the model. The key questions are about how generalisable and sustainable the model is.

The elements of the model as originally stated, and as described by the project's management committee in June 2002, are shown in Table 7.

Table 7 Objectives and interventions

The five objectives identified at the baseline	Activities described in June 2002
1. To provide a high quality and responsive service to patients and carers.	<ul style="list-style-type: none"> • Administration of the project by a board of governance including senior management from the GMAHS and MDGP plus representatives from pastoral care and the community; • Trained volunteer program and education programs for doctors, registered nurses, pastoral care and volunteers; • Establishment of a MDS that satisfies National Standards for Palliative Care; • Routine collection of baseline minimal data, monthly monitoring and progressive evaluation against nominated KPIs.
2. To ensure that appropriate care and expertise are available when needed.	<ul style="list-style-type: none"> ▪ Appointment of a Project Coordinator jointly funded by the GMAHS & MDGP for the initial 2 year term of the project; ▪ Joint agreement from all agencies on a single set of policy, procedures and clinical guidelines for the management of patients registered with the GAPS service; ▪ Trial of the PaLCIS palliative care information system as a patient registration and clinical information system. PaLCIS is compatible with the NSW Health SNAPShot information system; ▪ Trial of Palm Pilots to collect the MDS at the point-of-care and prompt for patient assessments.
3. To prevent inappropriate use of services such as use of Accident and Emergency or hospital in-patient services when better alternatives are available.	<ul style="list-style-type: none"> • Provision of a 24 hour 1800 number for advice, intake, referral and coordination of after-hours call-outs as required; • Formal agreement with GBH VMOs on-call for the transfer of GAPS-registered patients to a palliative care team medical officer next day following an emergency admission; • Formal GP on-call roster after-hours funded solely through MBS claims (organised and managed by MDGP). This includes an agreement that attendance for ED presentations will be encompassed within an MBS claim, and not levied against GBH as a GP-VMO call-back.
4. To use active multi-disciplinary care planning to permit	<ul style="list-style-type: none"> • Weekly case management review involving Oncology/Palliative Care Nurses, Community Nurses, Private Nursing Agency, GP representatives,

The five objectives identified at the baseline	Activities described in June 2002
coordinated services, anticipate patient problems and respond to patient preferences such as place of care.	Allied Health and liaising with Emergency Dept and Pastoral Care; <ul style="list-style-type: none"> • Pursuant to the weekly case reviews, coordinated, systematic uptake of EPC items is occurring; • An integrated patient-centred medical record that traverses all services involved in the patient's care.
5. To make this service available to all who need it within the community.	<ul style="list-style-type: none"> • Formal nursing on-call roster after hours including RNs from all agencies involved (organised and managed by GMAHS); • Joint intake decisions by the case management team.

The model is becoming more operationally defined and appears well prepared for its planned extension into other communities, in the first instance Coleambally, then Darlington Point, Hay and Hillston. There is interest in the GMAHS about the lessons from GAPS for subsequently taking something like this model beyond the current target areas to medium-sized centres such as Leeton, Narrandera and Finley.

2.7 Finance

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

Both the Commonwealth and the State have contributed additional funding. An enhancement under the NSW Complex and Chronic Care Program pays for additional costs in Griffith and \$10,000 is set aside to cover necessary assistance from the Area's Public Health Unit. The annualised State contribution of \$89,298 is used to cover .5 of the coordinator's position and .2 of the Area program manager, as well as goods and services (\$3,000) and the additional costs of the nursing on-call hours (\$22,500).

The Commonwealth contribution to the project (excluding evaluation costs) is \$288,859 over the 3-year period. This covers the other half of the coordinator, leasing the car and equipment and other incidental and administrative costs.

Much of the investment in the development of the interventions did not require enhancement to recurrent funding, e.g., integrated patient-centred records, clinical guidelines, GP on-call roster, case review meetings, information system implementation. The enhancement of recurrent funding covers those components related to the identified gaps in service delivery and where activity fell significantly short of National Standards, eg, the RN on-call roster, 1800 line, assorted variable goods and services linked to the increased activity.

Project funds are managed through transparent systems with regular monthly reports to the Governance Committee from MDGP and GMHS sources. At June 2002, the financial reports indicate the project requires about \$22,000 per year to maintain its level of activity in the Griffith area (this is excluding the coordinator salary). EPC items amounted to \$2,153, which was paid to participating GPs. Better estimates for the full costs of an expanded rural model will be available in the final report.

It's quite a cheap project – shared around three cost centres. We approve the nurses on call, consumables come from the oncology and palliative care cost centre, drugs are charged. Expensive medications are very small in number. The few consumables do not make a huge difference. (2002)

At the project's mid-point there is enthusiastic support from all stakeholders for the apparent cost-effectiveness of the interventions, but there is no secured ongoing funding. Stakeholders who are sharing risks and managing the funds (GP Division, Griffith Base Hospital, Community Health) expressed confidence that it would be possible to meet the modest increased costs of implementing the model. The relatively small investments in recurrent funds were mentioned by all informants as an early indication that the project can be made sustainable.

However, the service coordination role for GAPS beyond the life of the project is still an open question. The scope of the role, and how much can be built into existing arrangements, either in the hospital, in community health or in the Division, needs to be defined over the next stage.

A trust fund has been set up under the normal arrangements in place with the GMAHS as a restricted fund used to benefit palliative care services. The register of donations can be examined in the final report as evidence of the level of support the project has received within the local community.

2.8 Capital

The project uses a minimal amount of additional physical capital, which includes a new computer and the Palm Pilot data collection devices. The leased vehicle is shared between the project manager and the on-call nurses. Including decisions taken in June 2002 to make additional investments, the accounts show a total capital outlay to date of about \$2,500.

While this is a small project it is both complicated and sensitive and the appointment of the coordinator is confirmed at this mid-point to be a very good investment in both human capital and local capacity building.

On the 'human capital' side, the mix of clinical and managerial experience has enabled rapid progress to be made in the development of shared protocols and approaches. This has permitted the project to move from going 'live' on October 1, 2001 to having had 54 patients in June 2002, with 35 active patients¹⁵.

It cannot be safely assumed that this pace of service development would be possible in other settings. In Griffith it involved about three years of active preparation and a big increase in coordination costs, albeit absorbed by the stakeholders and helped by the evaluation and coordinator roles.

Comparisons with other localities in the next report will be essential to provide additional insights into the generalisability of the gains that have been made. The GMAHS has expressed a particular interest in using the model in Leeton and other similar-sized areas, which would replicate what has been done in Griffith, but each of these new areas would have their own associated outlying communities.

¹⁵ Minutes of the Board of Governance 1st July, 2002.

2.9 Summary of context issues

As the baseline findings highlighted, the history of the service difficulties and local planning prior to the project provided a strong base of support and fertile ground for the service developments. The extension of the rural model beyond Griffith in a planned and constructive way shows that the interventions are working and governance arrangements remain strong.

There were risks of an over-enthusiastic roll-out of the model before it was safe to proceed and the pre-conditions in other areas were in place. On-call rosters, community nursing or private nursing coverage, the ability to collect the assessment and outcome data, and GP coverage and interest, all needed to be assured first before the model is expanded to outlying areas.

The first four objectives of the GAPS model are being met:

- high quality and responsive service to patients and carers;
- appropriate care and expertise available when needed;
- prevention of inappropriate use of hospital services; and
- multi-disciplinary care planning to anticipate patient problems and respond to patient preferences.

The fifth objective (service available to **all** who need it within the community) is being tested in the next period with the roll-out of the model to towns beyond Griffith.

3 Activities

3.1 Governance

The Board of Governance continues to meet monthly and at times convenient to members and visitors (Area, State and Commonwealth officials have shown interest and attended). Membership has been stable except for a change of manager of the Griffith Nursing Service. The retiring manager has been invited to remain involved through the case conferences. The monthly reports from the project manager, reports from the two treasurers on the budget and finances, and reports from representatives' attendances at other meetings provide an accurate picture of the range of activities.

The governance committee ensures that feedback to the community is maintained, organises local events to mark project milestones or good news stories and ensures that the project can be seen to act properly in addressing its tasks. The evaluation team attends by tele-conference or in person and provides feedback and advice where appropriate.

3.2 Clinical activity

The steering committee attends to the more operational matters and helps to ensure the development and smooth operation of the policies and procedures. The meeting attended by the evaluation team worked efficiently for all those that attended and provided a venue for providers to ensure their work dovetailed with the plans and activities of the project manager/coordinator.

The case conference also appeared to operate very efficiently and to the satisfaction of participants under the direction of the coordinator. The review of patients, including their phase of care and symptom score data, as well as their current needs and the treatment plan, is obviously working well. This included contributions to improving the quality of pastoral care and the ability to respond to the death in a family context:

It worked really well with a family I knew; I was able to make a strong contribution to the case meetings. I was able to be far more effective in visiting since I knew more about what was going on in his head. (2002)

The coordinator was able to take the opportunity to update the patient records, ask for any missing data, and on request to review the data relevant to those patients being discussed. This role is in addition to the individual case management that is taking place. The activities and commentary focus attention on key data requirements and the importance of timely interventions around the changes in phases of care.

The recording and transcription of the meeting served as the basis for meeting the requirements of the EPC case conference item. The advantage for the GPs who attended is that the necessary paperwork can be completed for relevant patients on their behalf and this is very efficient in terms of the practice management issues involved.

3.3 Information System

As was noted in the baseline report, there are multiple demands on data collection. The project has a context of its own and is also part of larger systems that it is aiming to influence. It also needs to be evaluated. These larger systems include NSW Health program performance indicators and targets as well as GP-based care planning and accountability requirements.

The project can make the necessary connections to current data systems across the broader arena of health and community care. As result, the project's visibility has increased. The project has put considerable effort into minimising both the amount of duplication and the overall burden of data collection.

The larger system reporting requirements could be satisfied by the use of the AN-SNAP data collection system, including the *SNAPshot* software. Its capabilities include capturing clinical data, organising client information in terms of episodes (phases) of care and discrete classes of patients, and reporting to other data and accountability systems such as the Home and Community Care MDS and CIARR. *SNAPshot* can export to other Commonwealth programs (DVA, Aged Care) and provides a variety of reporting formats. 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 project¹⁶.

The *Pa/CIS* 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 purchase of additional Palm Pilots was approved by the Board of Governance in line with the roll-out to the out-lying rural areas. How the later down-loading into the patient information system from the remoter areas will work is not yet clear. The practical and clinical usefulness of the tools to the additional nurses who will be involved will be tested in the extended service roll-out period.

A detailed discussion of the information and data issues is provided in section 6 of this report.

3.4 Integration mechanisms

The evidence for progress on integration within the area is strong, and all informants said it is attributable to the activities and strategies adopted by the project to date. The integration elements cover:

- Case conferencing, processing of EPC claims and the active role of the GPs;
- Patient held record is being used;
- Standardised policies and procedures acceptable across disciplines;
- Hospital systems integration has improved: The hospital can ring the 1800 number from the emergency department to find out about a patient who arrives without their own notes.

It has been observed in the literature that integration is most often driven from a single perspective and success is often in the eye of the integrator¹⁷. In this sense there is evidence from the interviews that the integration of palliative care services may be seen as the fragmentation of oncology services.

¹⁶ Comments by project coordinator, November 2001, and in June 2002.

¹⁷ Leutz, W. (1999), 'Five Laws for Integrating Medical and Social Services: Lessons from the United States and United Kingdom', *The Milbank Quarterly*, 77(1): 77-110.

70% of admissions to GAPS come from oncology. There are trade-offs in the separation of PC and oncology – we would suggest there is strong case for keeping them together.
(2002)

This quote illustrates the variety of perspectives held by the stakeholders in the project. It is very important that the project maintains its multiple stakeholder approach that recognises both sides of the coin, integration and possible fragmentation. At best this issue will remain a central tension in the project which must be recognised by all parties as a natural product of the new model and addressed if and when the tension arises.

3.5 Benefits to consumers, carers and providers– education and feedback systems

The baseline report argued:

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 staff¹⁸.

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, are being brought together by the strategies approved by the Governance Committee, and all acknowledge there is still some way to go.

We see it still as a very medical model. Still some way to go as a holistic model. We are still evolving. (2002)

The system is still not working up to speed for some simple reasons ... doctors do not directly link in with the pastoral care network ... it's an introduction to truly holistic care - for the health professionals. Recording of spiritual needs is not adequate – what do spiritual needs mean? What does 'not recorded' (the largest category) mean? Categories need some adjustment on PaICIS (2002)

A set of brochures of practical information (How to Cope, Understanding Grief, Letting Go, Planning a Meaningful Funeral, Service Providers, Morphine) have been prepared for informing patients, carers and volunteers.

As a result, provider Q&A 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. (2001)

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). These are being formally addressed in constructive ways in the course of the project through the refinement of the policies and procedures. 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 pastoral care.

¹⁸ GAPS Pilot Program Coordinator's Report, August 2001 - ch1 reporting; ch2-4 referral, records and case conferencing; ch5 education p.15-6;

4 Impacts

A series of desired impacts are identified in the evaluation framework shown in Table 1. A combination of internal and external evaluation methods are used for monitoring the project and to document the intended and unintended outcomes and the impact on both palliative care services, and the wider system. These impacts include not only the achievements of the various interventions, but also the barriers encountered, the opportunities and the lessons.

This project poses new challenges for GPs similar to those the authors have reported elsewhere¹⁹. GPs who normally operate independently need to agree and utilise new treatment protocols, broaden the range of data which they normally use in their daily work such as that collected through the PaCIS schedule reported in Section 6. They need to operate in close contact with other disciplines from public and private agencies and demonstrate a heightened pattern of collaborative working.

The EPC items provide a basic framework through which this activity can be funded but considerable organisational engineering will be needed before normal operating patterns are changed.

The key shortage in a rural area is staff and expertise and it is very easy for short term organisational objectives to lead to a pattern of staff movements between organisations to take advantages of improvements in terms and working conditions. Such problems can be ameliorated when there is a pattern of inter-organisational collaboration such as that demonstrated by the working of the Griffith Private Nursing Service, the Community Nurses and the Oncology Nurses. Considerable efforts have been undertaken in the project, and these efforts continue to be needed to maintain these relationships.

4.1 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. These are presented in Table 8 and compared to the comments in June 2002:

Table 8 Providers' baseline views compared to comments at June 2002.

Views at the Baseline (August 2001)	Comments June 2002
<ul style="list-style-type: none"> All providers interviewed expressed <u>enthusiasm for the project</u> and the opinion that it was greatly needed to coordinate the care of palliative patients in the Griffith region. 	<ul style="list-style-type: none"> <i>It provides an opportunity for professional development, increasing my knowledge and skills. Also the same goes for other staff.</i>
<ul style="list-style-type: none"> Providers believe that there is <u>currently poor communication</u> 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. 	<ul style="list-style-type: none"> <i>Wonderful for the District Nursing service in caring for the palliative care patient at home, we are better informed, we have better information, the doctors are taking our calls, listening to us about patient issues. It was not unknown for them to refuse our calls before GAPS.</i>
<ul style="list-style-type: none"> No one interviewed had a real conception of <u>how many patients</u> would be included in the project. 	<ul style="list-style-type: none"> <i>There is a list of patients who are on the project. Patients are identified and GPs are informed of their patients who will be discussed at the Case Conference.</i>

¹⁹ Perkins D. and Owen A. (2002). GPs and the Care Net Trial. Chapter 7.1 in The Australian Coordinated Care Trials: Recollections of an Evaluation, Commonwealth Department of Health and Ageing, pp213-221.

Views at the Baseline (August 2001)	Comments June 2002
<ul style="list-style-type: none"> ▪ All expressed the view that palliative patients would have to be clearly defined ... not sure <u>who would actually qualify for the program</u> ... would it 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. 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. 	<ul style="list-style-type: none"> ▪ <i>Palliative care patients are not just oncology</i> ▪ <i>Some people who are in need of PC are not on the program. Why might patients choose not to be on the program? Why are people on the program inactive – Are these people in the stable phase?</i> ▪ <i>Patient's wife asking about going on GAPS program – she asked in the ambulance coming to Casualty</i>
<ul style="list-style-type: none"> ▪ Providers were unsure about how the project would <u>change their work practice</u>. 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. 	<ul style="list-style-type: none"> ▪ <i>Shared responsibilities help; nurses operate a triage system and GPs can get on with other hospital activity or work in their practices.</i>
<ul style="list-style-type: none"> ▪ All respondents expressed the view that the <u>case management meetings</u> 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 stress full job. 	<ul style="list-style-type: none"> ▪ <i>It (the CC) works very well, some (initial) teething problems with egos. Very much honed in the last 6 months. Working at different levels from clinical (data), from minds, from PaICIS</i> ▪ <i>The doctors often talk about their findings. Often we (nurses) get the patient's view about what has happened which might not always be accurate...it gives you a greater understanding about what the patient's situation is.</i>
<ul style="list-style-type: none"> ▪ All expressed the view that the project would require a <u>big culture change</u> for GPs and that it would take time for everyone to learn the system and to learn to communicate effectively. 	<ul style="list-style-type: none"> ▪ <i>GPs pretty happy if they can see progress without forms.</i> ▪ <i>Beyond case conferencing we contact GPs on a needs basis.</i> ▪ <i>At the CC we can get medication sheets of prescriptions written out since it is a face to face occasion. This is an alternative to a GP doing a visit.</i>
<ul style="list-style-type: none"> ▪ There were some <u>important administrative details</u> 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. 	<ul style="list-style-type: none"> ▪ <i>Some problems on home visits due to changeover of software. A is very happy with Palm Pilot, B less so</i> ▪ <i>The system is not fully implemented and needs a computer at Community Health, at GBH, and at Griffith Private Nursing.</i>

4.2 The record audit

The appropriate process to protect individually identified information, the availability of research resources at the right level of expertise, and the key terms to be used in a record audit at Griffith Base Hospital have been agreed in principle. Findings will be reported in subsequent reports and interpreted in the light of the expected overall improvements in using the data.

Briefly, the issues still to resolve in carrying out the record audit are around agreement on a work plan involving a series of steps. The selection of records to review is based on the diagnoses reported under PalCIS is the first step. A transparent process of selecting and counting the appropriately matched patients from the records is then required. Some verification that those selected have similar characteristics to those currently in the GAPS data base should then be undertaken by a clinically experienced rater.

Primary and secondary diagnoses and age are the main variables to match, but these cannot be expected to account for all the variables that are needed to select a sample of records of people who can be clearly characterised as matching the current profile of palliative care patients.

A checklist of patient characteristics, plus counts of bed days and outpatient visits is expected to be useful. Emergency Department admissions are registered under the EDIS system and these can be matched to the MRN of the selected sample to give a count of ED presentations. These would be compared to numbers in the GAPS data base.

4.3 Remaining management issues

At the baseline, informants for the evaluation raised a number of management issues that they expect will be resolved in the course of the project. These were re-visited at the second report.

Table 9 Management Issues

Baseline concerns	Comments in June 2002
<p><u>The coordinator position</u></p> <ul style="list-style-type: none"> ▪ How is the <u>project sustained</u> beyond his role? Who can take over? How do you provide the skills (when the existing infrastructure is thin)? ▪ How do you <u>improve services without creating dependency</u> in the main change agents? How does the coordinator do himself out of a job? 	<ul style="list-style-type: none"> ▪ <i>(Nobody) could take over. Project needs a leader. There is no-one else here who could do it</i> ▪ <i>I do not think it is self-sustaining on its own, it needs leadership</i>
<p><u>Maintaining improvements in services</u></p> <ul style="list-style-type: none"> ▪ What services do we provide? (is there any duplication of services, community nursing) ▪ What services for Hay and Hillstone (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? 	<ul style="list-style-type: none"> ▪ <i>You may go to get a piece of equipment and another service brings it the next day (eg. a commode)</i> ▪ <i>Possible to bring them to ED and then oncology nurse picks them up and takes them to the ward and brings in the GP on call for GAPS</i> ▪ <i>Hillston has no GP so if someone turns up at Hillston emergency department, they will ring the GAPS number or the GBH ED for advice.</i>

The project coordinator role can be seen as encompassing a number of activities such as project design and development, project maintenance and service management, project extension and making a wider contribution to palliative care service developments within GMAHS and more broadly.

It is therefore difficult to predict at this first stage what aspects of the coordinator role are needed to develop GAPS into a fully operating model in a rural area. Secondly, what is needed to extend it to more remote contexts, and thirdly, what is needed to maintain these changes in the long term and as part of a mainstream service.

Table 9 continued: Management issues

Baseline concerns	Comments in June 2002
<p>Key issues about the <u>GAPs model</u></p> <ul style="list-style-type: none"> ▪ 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? 	<ul style="list-style-type: none"> ▪ <i>Extension to Coleambally will require separate case conference meeting as inclusion would bog own Griffith meeting, teleconferencing is not so useful, so start with the 9 or so identified patients and do the GP training.</i>
<p>Issues around the <u>wider service system</u></p> <ul style="list-style-type: none"> ▪ 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. 	<ul style="list-style-type: none"> ▪ <i>No pastoral care in the protocols yet</i> ▪ <i>Death at home procedure has nothing about pastoral care. Nothing in the section on time of death</i> ▪ <i>Recording of spiritual needs – what do spiritual needs mean? What does not recorded mean?</i> ▪ <i>No psycho-social service being provided so not holistic</i> ▪ <i>Community health or Centacare provide counsellors. (Anglican) and catholic priest come to the hospital very regularly.</i> ▪ <i>We have links with other ministers, Roman Catholic, and can contact Sikh/Hindu easily through the multi-cultural council.</i>

Wider system impacts are apparent in the way that the model has highlighted existing gaps. Pressure is being exerted on the wider system to respond (ie where is the psychosocial backup?, where is the Area palliative care plan?) and this puts pressure back on the model to become more holistic, as well as to be clear how it fits in and how it will extend further out from Griffith.

These pressures mean in part that the expectations are rising and that the likely impacts will go beyond just the immediate stakeholders (ie those managing the budgets) to HACC, mental health, allied health, etc. It also means that planning in the GMAHS needs to be cognisant of the early lessons from GAPS. Local stakeholders have suggested that the fly-in model of specialist access via visiting clinics, while useful to palliative care in some parts of the area, may be less helpful

elsewhere. A partnership arrangement with a linked or mentoring centre and telehealth was thought to be a better alternative arrangement²⁰.

Table 9 Management issues

Baseline concerns	Comments in June 2002
<p>Issues around collecting <u>outcomes measures</u></p> <ul style="list-style-type: none"> ▪ Community health data: Can you separate the palliative care workload as a component of the total? Can the same be done to separate community 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. 	<ul style="list-style-type: none"> ▪ <i>PalCIS enables us to look at workload/hours. How much care does a patient need?</i> ▪ <i>Palm Pilot on balance is more useful than a nuisance. I was using it until the particular machine went wrong. It is one way to store data. I am ambivalent. Not sure that they are the best tool that is available.</i> ▪ <i>The Palm Pilot triggers things you should be asking the patient ... the pain.. the nausea, the bowels etc.</i> ▪ <i>Our terminology has changed, we now speak of the Karnovski score to see how dependant they are on nursing services.</i> ▪ <i>It's really good as a retrospective tool to be striving for excellence, seeing how situations developed or evolved and seeing what happened. Its really good for that.</i>

The patient held record, the Palm Pilot, the centrally-held (PalCIS) data and the on-call log, all give useful descriptions of the project's activity. How useful they are depends in large part on how the data are organised and fed back to the stakeholders.

The technical assessment of the information system components showed that the data collection burden has been well managed, and data are useful for the nursing clinicians. Its usefulness beyond the clinical domain depends on making improvements to how this clinical data might be reported and how more meaningful information can be made available.

The PalCIS software itself has some capability for better reporting longitudinal data. The recommended enhancements include exporting to Excel, graphing the results, and showing how different variables change over the phases of care. The data are not currently used to full effect in reporting by phase, linking related variables such as place of death and preferred place of terminal care, and the reports address one variable at a time.

²⁰ Report by management team, in submission to GMAHS, Future Scope, July 3, 2002.

5 Outcomes

5.1 The outcomes in June 2002 – what do we know?

While it is not possible to conclude that all problems have been solved, it is clear that the project has developed a shared model of care and has structures and processes in place that are useful in a rural area.

Table 10 Strengths identified at baseline and comments on sustainability

Baseline Conclusions	Report 2 Conclusions
The structures and relationships that underpin them, are strongly linked with mainstream services, consumer and community interests.	<ul style="list-style-type: none"> ▪ <i>This is still the case and particular efforts have been made to contribute to developments in GMAHS PC strategies</i>
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.	<ul style="list-style-type: none"> ▪ <i>These remain very strong holding regular meetings and ensuring progress on clinical, organisation and resource issues.</i>
The project has performance indicators and targets and there are systems to assess progress and take action if necessary.	<ul style="list-style-type: none"> ▪ <i>This is still the case</i>
The project is strongly documented which is vital given the significance of the multidisciplinary collaboration at its heart.	<ul style="list-style-type: none"> ▪ <i>The project has a wide range of detailed protocols agreed between the key parties, and these form the basis for action. There are still some gaps such as the integration of pastoral care activities and other psychosocial services.</i>
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.	<ul style="list-style-type: none"> ▪ <i>Multi-professional education is available to all participating agencies and is being made available to private nursing homes (now being integrated into the project). Attendance at education sessions is reported to be impressive compared with previous arrangements.</i>

Outcomes in terms of service enhancements are being documented clearly. However, this is not surprising given the extra resources and added expertise that has been involved to date. However, satisfactory answers to the key outcome questions depend on three additional pieces of work.

One piece of work is the interviews with patients and carers, the second is instituting the recommended modifications to the information systems and tools, and another is analysing the data from the hospital record audit and other area sources. These all need to be assessed in the next report. In the interim we have an inventory of progress as shown in Table 11.

Table 11 *Potential problems at baseline and progress in solving them*

Baseline	Report 2 Conclusions
Variable levels of confidence with IT, from IT phobic to quite literate – how will this develop?	<ul style="list-style-type: none"> • <i>Providers seem to have accepted the IT requirements, some more easily than others-</i> • <i>I really like the PP. It is really easy to use. It triggers things you should be asking..</i>
Careful that the project is not overly dependent on IT.	<ul style="list-style-type: none"> • <i>The PalCIS data at the case conference seems to support rather than dominate discussion.</i>
The 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.	<ul style="list-style-type: none"> • <i>There are gaps in the notes. People will visit and not document...the patient will tell you that someone has visited but there is not a note on the record.</i>
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.	<ul style="list-style-type: none"> • <i>Note that monitoring has shown there have been no referrals of children to date, and so this view has continued to be held.</i>

In general the project has been effective at identifying and remedying problems as they have arisen. The project manager and others have begun to make a larger contribution to GMAHS discussions on the pattern of PC services which is a valuable outcome but may have slowed the speed at which some of the issues have been resolved such as the pastoral care and psychosocial interface.

Reduced use of the Emergency Department seems likely although more data is needed and a longer time scale on the data will help because of the small numbers of people involved.

The additional costs of the 1800 number and nurse on-call roster are not regarded as expensive and the GP contribution is largely funded by standard MBS items.

The use of EPC items is impressive but restricted to the case conferencing items since the care planning items are regarded as administratively complex and practically burdensome.

Where nurses have substituted for GPs there is some evidence that GPs are able to use their time for procedural and other work which they regard as of high value.

The EPC items may provide a source of ongoing funds that can be used to fund a range of professional staff and so help sustain the service beyond the project phase.

5.2 *Next phase of research - record audit and interviews with patients and care givers*

Many complex and chronic conditions as well as some acute ones, share the mix of diagnoses listed for those people in the GAPS data base. So a sample of records, based on age and diagnoses, will be the starting point. Ideally for a study of this type, the sample should be collected of about 1:4, meaning about 200 records would be needed to have the most useful analysis. It is unlikely the final sample to analyse will be that large and this is a limitation of the small size of the original GAPS sample from which to seek matching records. A list of the patients' diagnoses as entered into the PalCIS database is included at Appendix 3.

To this point we have not included the clients of the GAPS program or their families in our interviews. We have delayed talking to this group of people in order to allow the program to become established and to let it build up a client group from which we can make our sample.

We acknowledge that interviews with this group of people are sensitive and difficult, and we do not wish to place any undue stress on respondents. However we consider that interviews are essential to find out how the program works through their eyes and how they think the service has changed. Most importantly the interviews provide us with qualitative information about quality of life, to supplement the observations made by the GAPS staff and the self report measures in the information system. We will be in a position to report any issues that appear to be compromising quality of life back to the GAPS team, as often clients are concerned about reporting issues that may appear to be trivial, or outside the medical model.

Nightingale (2000: 40)²¹ provides a useful checklist of components of a palliative care program that may be of interest to consumers.

Consumer issues:

- Is my pain (or other symptoms) controlled to a level that I can tolerate, and does this allow me to do what I want to do (within the limitations of disease and disability)?
- Does my health care worker appear to be knowledgeable about my condition and the alternatives for managing my problems?
- Are my health care workers concerned for my emotional, spiritual and social needs?
- Do my health care workers help me to understand my situation by providing me with information and involving me in making decisions about everything that affects me?
- Do I have a choice about where I am cared for? Am I able to return to my home in a rural or remote location and still feel that I will receive the care and advice that I need?
- Are my symptoms and other problems regularly reassessed?
- Is communication amongst members of my team effective ie, do they keep each other informed or do I have to keep telling everyone the same thing?
- Is my health care service available to me 24 hours a day, 7 days a week if I need it? Are the contact details clearly written so that I can follow instructions in an emergency?
- On a scale of 0 to 10 how would I rate the palliative care I am receiving? Are my needs being met to my satisfaction?

For Carers:

- Do they offer suggestions and other services to assist me in my caring role?
- Are my health care workers concerned for how I am managing in my caring role?
- Is there someone who will contact me and put me in touch with support if I need it, after the person I am caring for has died?

In addition to these general factors which contribute to a good palliative care program, we also wish to explore the factors which are specific to the GAPS Program, such as the 1800 number. We want to discuss the process of decision making that people go through when using this number and how comfortable people feel accessing 24 hour care.

²¹ Nightingale, E. 2000, 'Quality in palliative care' *The Australian Consumer*, 3: 39-40.

Method

We have decided to recruit respondents through a letter of invitation, which explains to them that we are looking at how to provide a best service and that their perspective either as a patient or a carer is very important. But will also emphasise that their decision not to be involved will not affect the service they receive in any way.

We propose to send the letter to each of the clients who are currently part of the program. Willingness to be involved may be followed up during the visits from palliative care nurses. The development of questions will be done in consultation with members of the GAPS team and especially those people who are involved in the provision of pastoral care. In this way we will not only ascertain what issues may be most important to discuss from their perspective, but also how to address these issues in the most sensitive way.

6. Capability and use of the GAPS information systems

6.1 Introduction

The project requires client data for various purposes, to assist client-level clinical decisions, for management purposes, and to enable the trial to be evaluated. It also needs to meet various standards that stem from the wider health system. Principal among these are the data items required by the NSW Health program performance indicators, and those linked to the reimbursement of GP care planning.

The project has developed its own information system, based primarily around the PalCIS clinical information system. Nonetheless, it has spent considerable time to ensure that it is acceptable to staff across the broader arena of health and community care services. The project has tried to minimise both the amount of duplication and the overall burden of data collection. In so doing, it has had to work in an environment in which access to computer technology cannot be taken for granted, and in which staff may not routinely use computers.

The system is not fully implemented and needs one service/computer at Community Health and another at GBH and perhaps one at Griffith Private Nursing. The history of poor data collection in the past takes some cultural shift. The Palm Pilot makes it simpler. (2002)

The PalCIS system was selected by the project management on the basis that it is purpose-built to be clinically sensible for use in rural palliative care services. In particular, staff can enter data when on call using a Palm Pilot and later download this information to the central client information system. The software is still being actively developed in WA, and so there is the possibility of the project collaborating with the developers to ensure it suits the purposes of the project and reporting evaluation.

6.2 Routine Data collection

6.2.1 Data items within the PalCIS system

The PalCIS software permits the collection of various client and service related information. This includes: details about the initial referral of a client to the palliative care service, the client's clinical condition and how they would prefer to be cared for, information about the principal carers, and the death of the client. Data can be entered on episodes of direct care by various services (such as inpatient, outpatient, GP, domiciliary nursing), and indirect clinical activities (such as case conferences).

The system also supports the collection of other client related health-status information. The supported instruments include:

- the Karnovsky index, which rates the ability of a client to perform their normal daily activities;
- a summary system assessment which covers insomnia, appetite, nausea, bowel problems, breathing, fatigue, pain, current Quality of Life, general health perception and a wound index. A summary PBN score is derived by summing the scores from a subset of these items (nausea, bowel problems and pain);
- the RUG-ADL functional assessment score, and the AAHPC Problem Severity Index.

Client information is primarily organised around the concept of episodes (phases) of care. The five item classification delineates between the following states: Stable, Unstable, Deteriorating, Terminal, and Bereavement. This information, together with information on the client's age, RUG-

ADL and Problem Severity scores, should allow the grouping of clients to discrete classes. By so doing, the clinical level data should be convertible to information about expected resource use, which would be useful for management and evaluation purposes. In this regard, the PaICIS software seems compatible with the larger system reporting requirements due to the possibility of collecting the items required for relevant casemix classification systems.

6.2.2 Characteristics of the data collected so far

The project provided data describing the care of enrolled clients up to the end of May 2002. The database contained 52 clients (plus the PaICIS example patient). Twenty of these clients were enrolled in the month the project began (October 2001), with 41 clients being referred by the end of January 2002. The phase of most clients (n=37) at the time of referral was rated as stable; 10 clients had an initial phase of deteriorating, three were rated unstable, while two were rated terminal. There have been 27 deaths among these 52 clients. Eight of these clients are still rated as active, with a current phase of bereavement.

There was a wide range of primary conditions among the 52 clients, thus limiting the usefulness of this information for analysis. Of more use may be the data of the generic health status measures. So far, the project has made use of all instruments within PaICIS. On most occasions, the scales appear to be administered on the same visit (see Table 12). The number completed per client varies however. Table 12 indicates that 10 clients do not have any health status information, and another eight have one record. However, there are some clients who have 12 or more records. The number of assessments that a client had was not strongly related to the length of time the client has spent in the project.

PaICIS contains separated data entry screens for the SAS, Karnofsky and AN-SNAP (RUG-ADL and Problem Severity) instruments. There is the potential for different phase information to be entered, as the phase information is entered on each occasion, but this had not occurred in the collected data.

Table 12: Combinations of health status measures completed at visits

Combination of health status scales	Frequency
All scales	214
SAS and Karnofsky	10
SAS and SNAP	11
Karnofsky and SNAP	25
SAS only	32
Karnofsky only	11
SNAP only	8
Visits at which at least one scale completed	311

Table 13 *Distribution of health status records across clients*

Number of records	Clients with at least one record	Clients with SAS data	Clients with Karnofsky data	Clients with SNAP data
0	10	13	12	12
1	8	10	11	12
2	4	4	5	5
3	7	6	5	4
4	3	2	2	2
5	0	1	2	2
6	2	1	0	1
7	2	1	2	1
8	2	2	1	1
9	1	2	0	2
10	3	2	4	2
11	0	1	1	1
12	1	0	1	1
More than 12	9	7	6	6

In relation to the use of the data to assign clients to palliative care classes, there was a change of phase between subsequent assessment visits on 50 occasions but the relevant items were not collected on all occasions; they were missing for 13 visits. This effectively prevents the allocation of clients to palliative care classes at this time.

Within the SAS, RUG-ADL and severity scale records, not all fields are completed. In relation to the SAS items, each record contained at least the nausea, bowel problems and pain scores, thus enabling the PBN score to be computed. The items of insomnia, appetite, breathing and fatigue are missing in between 15 to 22 cases. The Quality of Life, Satisfaction and Wound Index are rarely collected.

Each of the AN-SNAP records contained values for all items of the RUG-ADL scale. However, 19 of the 258 records were missing values for all components of the severity scale.

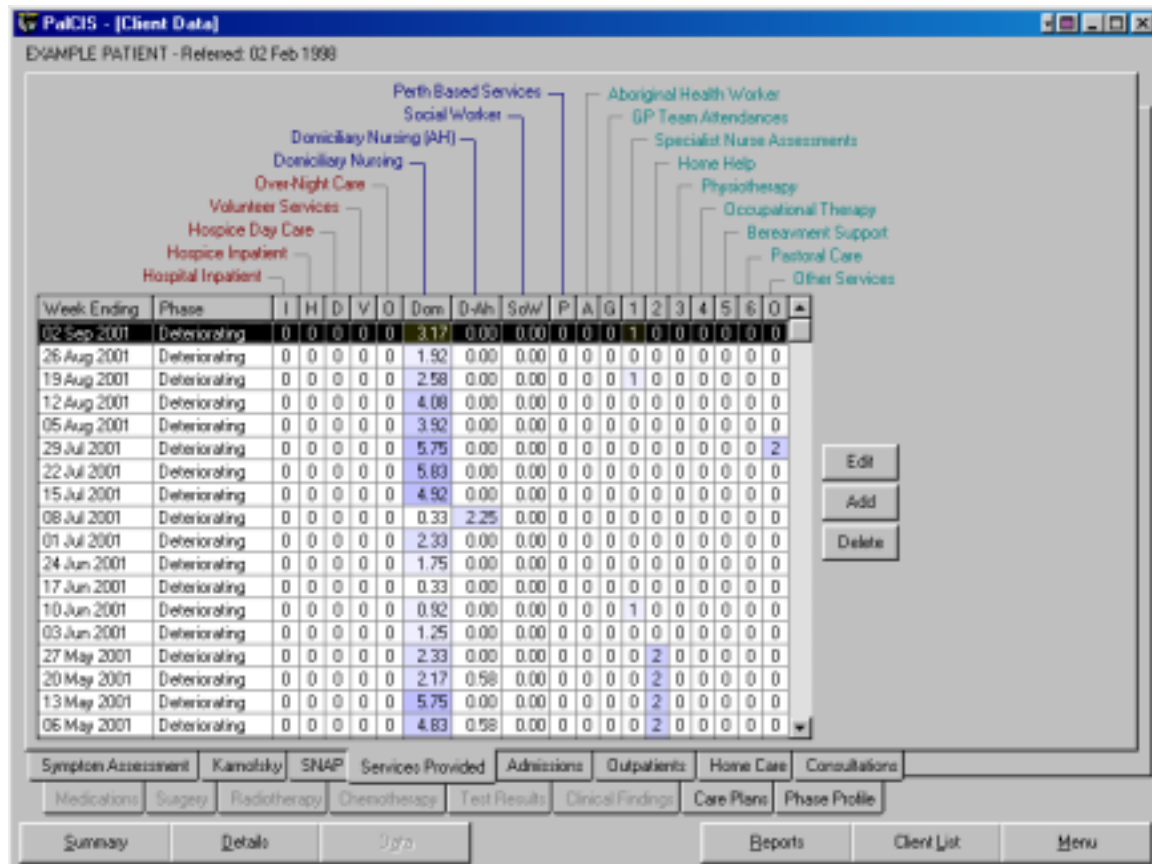
Data collected on the care delivered to clients covered the following services at the time of the data extraction:

- Home Care (domiciliary nursing);
- Hospital admissions;
- GP case conferences.

Information on these episodes of care were entered in the two ways allowed by the PalCIS system: via screens for each type of service, and in terms of the overall amount of care delivered, by service type, during a week. PalCIS also has a dedicated screen for entering data on outpatient visits (but no data were entered about such visits). It seems other dedicated screens are planned for chemotherapy, radiotherapy, medications and surgery, but these are currently not operational.

The screen allowing the entry of a weekly summary of services received allows information on a range of other services to be included (see Figure 1), although curiously outpatient services are not included. Another omission of importance in the Griffith trial is the lack of a dedicated field to record visits to a hospital emergency department. The inappropriate use of such services was one of the issues the project sought to address.

Figure 1 Date entry screen for the weekly summary of services received (dummy data)



Week Ending	Phase	I	H	D	V	O	Dom	D-Ah	SolW	P	A	G	1	2	3	4	5	6	0
02 Sep 2001	Deteriorating	0	0	0	0	0	3.17	0.00	0.00	0	0	0	0	1	0	0	0	0	0
26 Aug 2001	Deteriorating	0	0	0	0	0	1.92	0.00	0.00	0	0	0	0	0	0	0	0	0	0
19 Aug 2001	Deteriorating	0	0	0	0	0	2.58	0.00	0.00	0	0	0	1	0	0	0	0	0	0
12 Aug 2001	Deteriorating	0	0	0	0	0	4.08	0.00	0.00	0	0	0	0	0	0	0	0	0	0
05 Aug 2001	Deteriorating	0	0	0	0	0	3.92	0.00	0.00	0	0	0	0	0	0	0	0	0	0
29 Jul 2001	Deteriorating	0	0	0	0	0	5.75	0.00	0.00	0	0	0	0	0	0	0	0	0	2
22 Jul 2001	Deteriorating	0	0	0	0	0	5.83	0.00	0.00	0	0	0	0	0	0	0	0	0	0
15 Jul 2001	Deteriorating	0	0	0	0	0	4.92	0.00	0.00	0	0	0	0	0	0	0	0	0	0
08 Jul 2001	Deteriorating	0	0	0	0	0	0.33	2.25	0.00	0	0	0	0	0	0	0	0	0	0
01 Jul 2001	Deteriorating	0	0	0	0	0	2.33	0.00	0.00	0	0	0	0	0	0	0	0	0	0
24 Jun 2001	Deteriorating	0	0	0	0	0	1.75	0.00	0.00	0	0	0	0	0	0	0	0	0	0
17 Jun 2001	Deteriorating	0	0	0	0	0	0.33	0.00	0.00	0	0	0	0	0	0	0	0	0	0
10 Jun 2001	Deteriorating	0	0	0	0	0	0.92	0.00	0.00	0	0	0	1	0	0	0	0	0	0
03 Jun 2001	Deteriorating	0	0	0	0	0	1.25	0.00	0.00	0	0	0	0	0	0	0	0	0	0
27 May 2001	Deteriorating	0	0	0	0	0	2.33	0.00	0.00	0	0	0	0	2	0	0	0	0	0
20 May 2001	Deteriorating	0	0	0	0	0	2.17	0.58	0.00	0	0	0	2	0	0	0	0	0	0
13 May 2001	Deteriorating	0	0	0	0	0	5.75	0.00	0.00	0	0	0	2	0	0	0	0	0	0
06 May 2001	Deteriorating	0	0	0	0	0	4.83	0.58	0.00	0	0	0	2	0	0	0	0	0	0

In addition to the two sets of data not being consistent in the services covered, the two sets of data did not always match. For example, two records were entered on the detailed admission screen (one each for two clients), whereas there were 30 weeks in which inpatient days were recorded against 12 clients. Moreover, the place of death for 10 of the 27 clients who had passed away was recorded as in hospital. Similarly, the 25 detailed records on Home Care visits under-reported the episodes of care in the services screen. There were 18905 minutes of domiciliary nursing recorded during normal hours and 530 minutes of after hours nursing. Yet, 8 of the 25 detailed records occurred in weeks against which no nursing time was recorded. Finally, the weekly summary data recorded 654 case consultations compared to 156 detailed records.

It is worth emphasising that the two service screens capture the phase information differently. On the dedicated screens, phase is associated with a particular event, and if a series of events happen on consecutive days, the phase may change on a daily basis. The weekly summary screen allows phase to be entered only on a weekly basis; it is not possible to capture changes of phase within a week. This introduces a degree of approximation that, ideally, should be avoided as well as the potential for inconsistent information to be entered (not only between the service information but also with respect to the health assessment information). In addition, if no summary service information is entered (for example, because no services were provided that week), there is a gap in the sequence of weekly phase data. In many instances, it might be safely assumed that the phase has not changed. However, as PalCIS does not force the service and assessment data to be consistent, it is possible that a change of phase may have occurred in a missing week.

The implications of these data difficulties are discussed in Section 6.5 and recommendations are included at Section 6.7.

6.3 Analysis of collected data

6.3.1 Movement of phases

From the time of enrolment to the end of the data collection period (1 June 2002), the 52 clients in the database had 127 phases of palliative care (see Table 14). The majority of these were spent in the stable phase, both in terms of number and duration. In contrast, the average time spent in the deteriorating and unstable phases was about 1 month.

Table 14 Summary of phases among the 52 enrolled clients

Phase	Number of phases	Total days spent in phase	Incomplete phases	Average duration of phase (days) *
1	50	4246	21	146
2	18	579	2	36
3	23	627	2	30
4	9	125	0	14
5	27			
Total	127	5577	25	44

* incomplete phases treated as censored observations

In the cases where complete information was available, there was no dominating sequence of phases among clients (Table 15). The majority of clients had 2 or 3 phases in a sequence (including bereavement), though several had seven phases. Amongst the clients with a sequence of 2 or 3 phases, the sequence tended to conform to expected patterns, although there is perhaps a surprising number of deaths while patients are in phases other than terminal. For longer sequences, the patterns were arguably less expected. For example, the six four-phase sequences were {1-2-1-5}, {1-3-1-5}, {1-4-1-5}, {3-1-2-5}, {3-2-1-5}, {4-1-4-5}. In cases where incomplete information was available, most clients remained in the stable phase.

Table 15 Common sequences among the 52 clients

Complete phase sequences	Frequency	Incomplete phase sequences	Frequency
1-5	6	1-	20
2-5	1	3-2-	1
3-5	2	1-3-1-	1
4-5	1	1-2-3-	1
1-2-5	1	1-2-3-2-	1
1-3-5	2	2-3-1-3-	1
3-4-5	3		
4-phases	6		
5-phases	3		
6-phases	0		
7-phases	2		
Total	27	Total	25

One might expect that clients with the greater number of phases would have the longer duration within the trial. No such pattern exists. Indeed, 17 of the 18 longest enrolled clients have stayed in one phase (stable) for the complete time. The reason for this is probably due to differences in the health status of the clients when enrolled. Those clients enrolled in a phase other than Stable tended to have the phases of shortest duration.

6.3.2 Health status scores

As noted earlier, PaICIS has facilities to store various patient health status scores, notably the Karnofsky index, the PBN score, and the RUG-ADL and Problem Severity Index required by the AN-SNAP classification.

The distribution of patient scores for each of these instruments was analysed, stratifying the data by phase. However, it is worth noting that the interpretation of these distributions is not straightforward. First, there were no data for some phases of care. This means that there was no information for some patients although they had such a phase recorded. Second, in other instances, more than one assessment was conducted during a phase. This would not be a concern if each assessment score was independent, but it is likely that there will be some systematic movement among scores within each phase.

The distribution of scores for the four instruments are summarised in Table 16. For the PBN scores, there appears to be no strong relationship between phase and the recorded value. Stable clients have generally low scores; 95% have values of 12 or less. There is a greater spread of scores among patients in the other phases, though 50% of the scores are still around 2-3. In relation to the pain component, pain was on scored above 5 on 20 occasions. Interestingly, 9 of these occurred in stable phases. In most cases, the period over which the pain score was above 5 did not last long.

The Karnofsky performance scale is a brief functional assessment that uses an 11-point scale from 100 (normal, no complaints) to 0 (dead); intermediate points include 70 (cares for self), 50 (requires considerable assistance) and 30 (almost completely bed-fast). As such, it is not surprising that there is a relatively strong relationship between phase and the Karnofsky score. There would appear to be a few trivial data issues, however, given the rating of "dead" for someone in the terminal phase.

The RUG-ADL scale is also a functional dependency instrument, measuring the assistance someone needs with bed mobility, toileting, transfer, and eating. It is somewhat surprising, therefore, that there was not a strong relationship between phases and the distribution of scores. By way of comparison, Figure 2 shows the scores from both the present study and the AN-SNAP classification study (using the scores of community palliative care patients). The relationship between phase and the RUG-ADL is clear in the larger AN-SNAP study. This may be due to the small project sample size, and, if the sample of clients was increased, a similar pattern might appear.

Table 16 *Distribution of assessment scores by phase for the PBN, Karnofsky, RUG-ADL and Severity Index instruments*

PBN scores (score increases with worse health)

Phase	Number of scores	#Pats with a score	#Pats with this phase	Minimum	25 th percentile	Median	75 th percentile	Maximum
1	120	30	44	0	0	2	5	25
2	52	13	14	0	0	2.5	10	23
3	73	17	18	0	1	2	9	16
4	20	8	8	0	0	0	9	16
5	2	2	27					
Total	267							

Karnofsky scores (score decreases with worse health)

Phase	Number of scores	#Clients with a score	#Clients with this phase	Minimum	25 th percentile	Median	75 th percentile	Maximum
1	114	30	44	30	50	60	80	100
2	53	13	14	20	30	50	60	100
3	69	17	18	10	30	40	50	90
4	20	7	8	0	20	20	40	60
5	4	4	27					
Total	260							

RUG-ADL scores (score increases with worse health)

Phase	Number of scores	#Clients with a score	#Clients with this phase	Minimum	25 th percentile	Median	75 th percentile	Maximum
1	115	30	44	4	4	4	10	15
2	53	13	14	4	4	6	10	15
3	69	17	18	4	10	14	15	18
4	19	7	8	6	10	12	15	18
5	2	2	27					
Total	258							

Severity scores (score increases with worse health)

Phase	Number of scores	#Clients with a score	#Clients with this phase	Minimum	25 th percentile	Median	75 th percentile	Maximum
1	107	29	44	0	4	4	6	12
2	52	13	14	0	4	5	7	12
3	64	17	18	0	5	7.5	9	11
4	14	5	8	0	0	0	5.75	11
5	2	2	27					
Total	239							

There was a positive correlation between the scores of the Karnofsky and the RUG-ADL scales, and there might be some argument to collect only one of these functional scales (Table 17). However, in some respects, they are complementary. The middle Karnofsky items are not particularly precise:

- 70 Cares for self, but less than normal activity;
- 60 Occasional assistance, mainly self-care;
- 50 Requires considerable assistance;
- 40 Bed bound > 50% of the time;
- 30 Almost completely bed-fast.

The RUG-ADL gives a much greater level of detail, and distinguishes between a variety of patients with the same Karnofsky score, especially those rated 50. In contrast, the Karnofsky scale distinguishes between patients who are rated 4 on the RUG-ADL. Of course, due to the limited sample size, a final conclusion about their relative merits cannot be drawn. Consequently, it seems desirable for the study to continue collecting both – not least because there appears to be considerable local support amongst clinicians for the Karnofsky scale, and the RUG-ADL is required for the AN-SNAP classification. However, the distribution of univariate RUG-ADL scores per phase, and some of the more extreme coordinates (for example, (30,4) and (50,18)) suggest that the scoring of these instruments might need to be examined, and the need for further training assessed.

Figure 2 *Quartiles of the distribution of RUG-ADL and Problem Severity scores by phase as recorded in the Griffith and AN-SNAP studies*

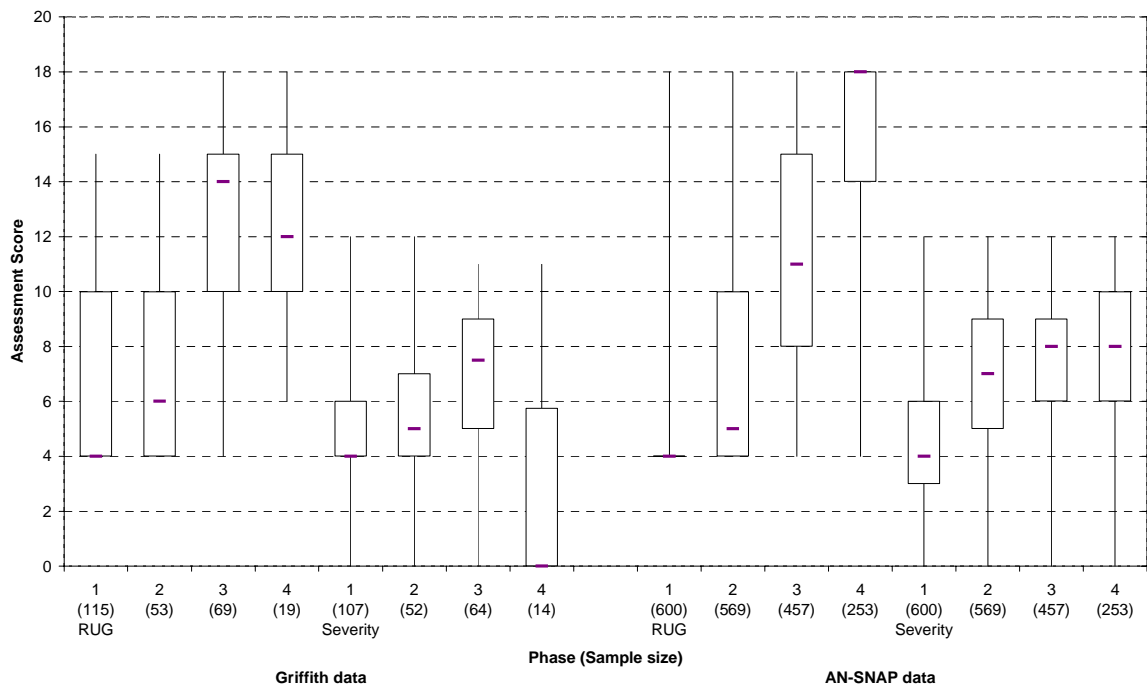


Table 17 *Distribution of Karnofsky and RUG-ADL scores*

RUG-ADL scores	Karnofsky scores										Total
	10	20	30	40	50	60	70	80	90	100	
4			2		3	10	8	28	23	1	75
5					3	1	2				6
6			1	4	3	12	1				21
7				2	2	1					5
8			3	2	2	4		1	1		13
9			1	2							3
10			4	5	10	8					27
11		2	4	2	4	1					13
12		3	5	1	1						10
13			3		8	1					12
14		2		2	8						12
15	2	16	8	4	1	2					33
16			1		2						3
17		1			1						2
18	2	1			1						4
Total	4	25	32	24	49	40	11	29	24	1	239

As in the case of the PBN instrument, there does not appear to be a strong relationship between phase and the scores of the AAHPC Problem Severity Index among these 52 clients. The shift in scores by phase was also not substantial in the larger AN-SNAP study, and in comparison, there is similarity in the distribution of scores for phases 1, 2 and 3 (see Figure 2). The scores among the clients for phase 4 are less similar, but there were very few observations in the Griffith data set. In addition, the high number of clients with a score of zero in this phase suggests that these may be missing values, possibly due to the rater not wanting to/being able to assess the client with this instrument

6.3.3 Service utilisation

Due to incomplete nature of the detailed records, the analysis of service utilisation data was limited to the table of weekly summaries, and only examined the services provided by phase. Moreover, due to the aggregate nature of this information, with phase only being available by week, no attempt was made to group the data into AN-SNAP classes and examine service patterns in this way. Neither was an attempt to examine service patterns by range of any of the health status scores (Karnofsky, PBN, RUG-ADL, or Problem Severity Index).

The number of units of service for each of the fields containing data are summarised in Table 18. The use of services is stratified by phase in terms of the total recorded, the use of services per complete phase, and the use of services over a week.

Table 18 Summary of service utilisation data collected in PalCIS on the 52 clients

Services	Unit	Phase				
		Stable	Unstable	Deter.	Terminal	Bereav.
Hospital Inpatient	Days	22	55	25	1	7
Dom. Nursing	Mins	9685	3530	3660	1275	755
Dom Nursing (After-hours)	Mins	90	300	0	140	0
GP team attendance	Occ	525	56	45	13	15
Other services	Occ	42	8	5	4	7
Number of phases		50	18	23	9	27
Number of complete phases		29	16	21	9	27
Number of days		4246	579	627	125	0
Services per complete phase						
Hospital Inpatient		0.76	3.44	1.19	0.11	0.26
Dom. Nursing		333	221	174	141	28
Dom Nursing (After-hours)		3	19	0	16	0
GP team attendance		18.1	3.5	2.1	1.4	0.6
Other services		1.5	0.5	0.2	0.4	0.3
Services per week						
Hospital Inpatient		0.04	0.66	0.28	0.06	
Dom. Nursing		15.97	42.68	40.86	71.40	
Dom Nursing (After-hours)		0.15	3.63	0	7.84	
GP team attendance		0.87	0.68	0.50	0.73	
Other services		0.07	0.10	0.06	0.22	

Service use per phase can be seen to be highest for the 'stable' phase (except for inpatient days and after-hour nursing). This reflects the average duration of the phases. When examined on a weekly basis, a different pattern appears. The use of domiciliary nursing follows the expected trend of increasing from the 'stable' to 'terminal' phase. This is also true for after-hours nursing care except for the deteriorating phase (though this might be due to missing data). The GP team reviews occur roughly once every 1 or 2 weeks for each client, and frequency seems not to be related to phase. Most inpatient days occur in the unstable or deteriorating phase. The low number in the terminal phase might be due to "at home" being the common preferred place of death.

However, while the pattern is consistent with expectations, the absolute figures should be treated with caution. As noted earlier, there are various reasons to suspect that not all services received have been entered into PalCIS. Consequently, the level of service use as shown in Table 18 is likely to under-estimate the real levels.

6.4 Viewing data and extracting aggregate reports in PalCIS

The clinical usefulness of a client's data in the hands of an experienced clinician is an issue separate to how that data are best reported for management purposes. The clinical domain is where project staff state that having the system does help, probably because, at a client-level, PalCIS can provide a longitudinal picture of the person's:

- health assessment scores;
- service use;
- sequence of phases.

It seems that this faithfully represents the clinical profile, and can be readily interpreted by a clinician. A noted benefit was in the communication of client data,

Its advantage is the ease of transferring data. I've been able to look back and see over a palliative care illness how well I've been able to control symptom management and how well the team has done that. (2002)

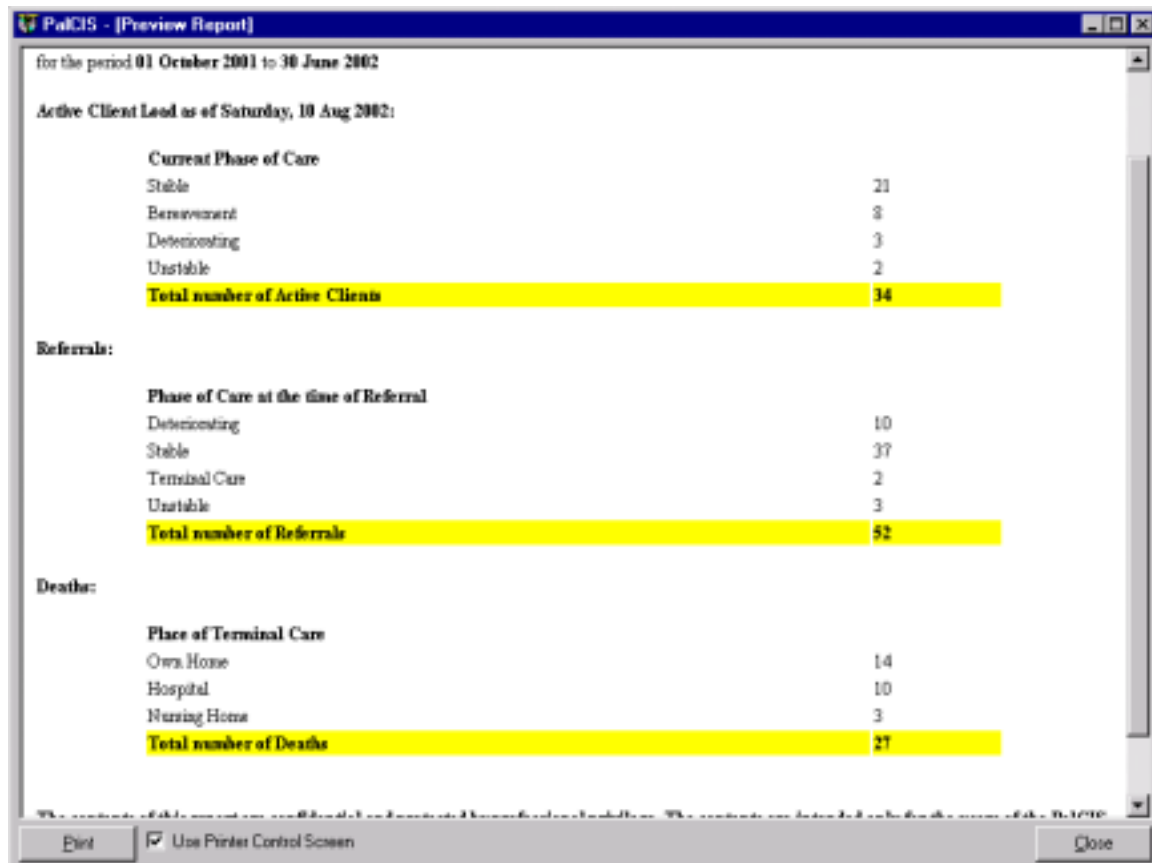
Nursing staff reported that there were practical hardware limitations - they needed more direct access to the PalCIS data and to desktop computers. In some cases, the resources are missing so staff pointed out that this is a barrier to overcome if they were to use the data to inform and improve their clinical effectiveness. At this stage, the full set of data is only easily available to the project coordinator.

The PalCIS system contains four standard reports, plus an ad hoc reporting system, that enable users to examine overall patient experiences and total patterns of care. The four standard reports, which provide information over a user-defined period of time, are:

- The global summary report, which can provide information on current active clients, who was referred and died over the specified period, a summary of the number of patients that used different services and the amount of service used;
- The referrals summary, which can provide information on who was referred, aggregate demographic statistics (age, sex, financial status), their distribution across diagnostic categories as well as individual diseases, referral source and reason for referral;
- The deaths summary, which can provide information on who died, aggregate demographic statistics (age, sex, financial status), their distribution across diagnostic categories as well as individual diseases, by preferred and actual place of terminal care;
- The service usage summary, which gives the total number of services used by service type of time (over 1-, 2- or 4-week intervals).

The project is using each of these reports but it is unclear how well they support the management of the activities. This is partly because of the small numbers of people in the program (52 in our data), but also because the routine reports available under PalCIS do not present the data in the most meaningful way. For example, the global summary report does not provide a complete picture of the clients' movements, mixing both phase and service utilisation information (see Figure 3). To provide a complete picture, it is necessary to have information about the number of clients in each phase at the start of the analysis period, and about the movements of patients between phases during this phase. This could be provided in terms of the number assigned each type of phase, which would be of use to monitoring changes in demand for services, or in terms of the sequence of phases, which would be of use to show in which clients there had been change.

Figure 3 Example of client movement information in the global report



PalCIS - [Preview Report]
for the period 01 October 2001 to 30 June 2002
Active Client Lead as of Saturday, 10 Aug 2002:

Current Phase of Care	
Stable	21
Reassessment	8
Deteriorating	3
Unstable	2
Total number of Active Clients	34

Referrals:

Phase of Care at the time of Referral	
Deteriorating	10
Stable	37
Terminal Care	2
Unstable	3
Total number of Referrals	52

Deaths:

Place of Terminal Care	
Own Home	14
Hospital	10
Nursing Home	3
Total number of Deaths	27

Print Use Printer Control Screen Close

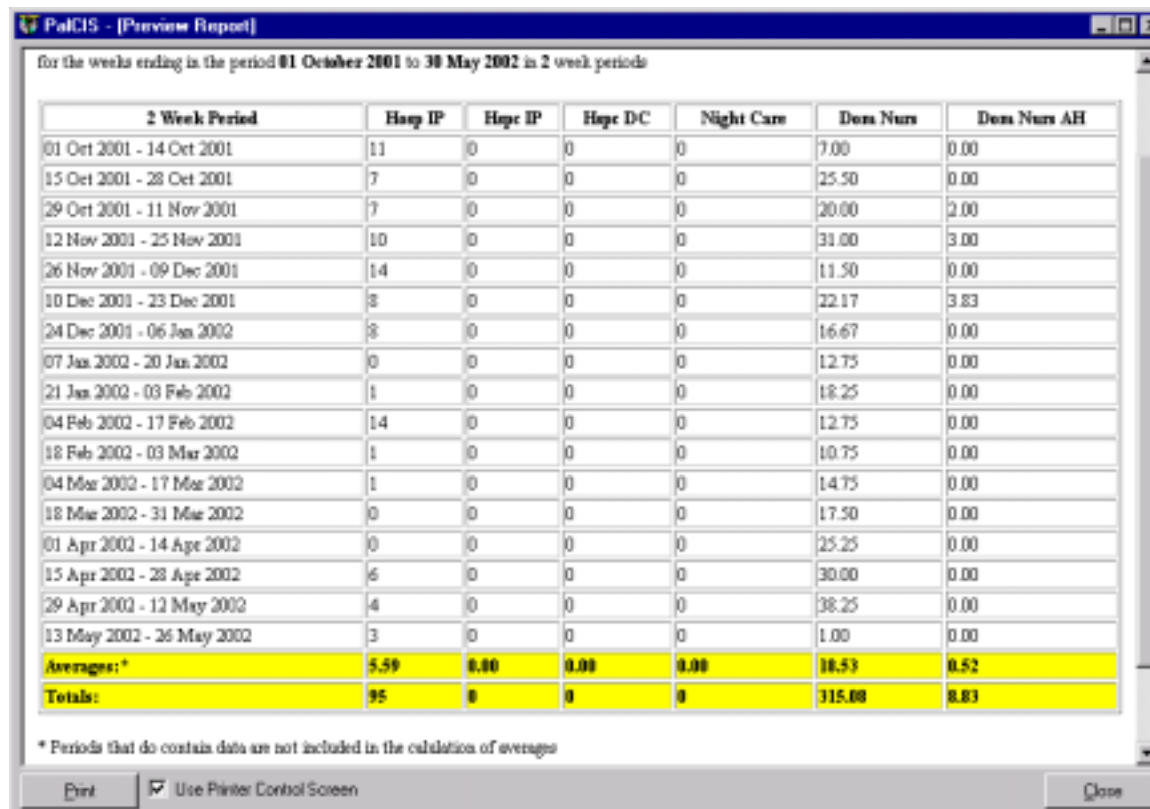
Another general weakness of the standard PalCIS reports is the tendency to present information for only one variable at a time. From a managerial perspective, it would be more useful to provide information by related variables. For example, the death summary report presents separate tables for preferred place of death and actual place of death (see Figure 4), where it would be helpful to show this information as a cross-tabulation using both variables. This would show how many clients had been able to die in their preferred location. More generally, as phase is a fundamental variable describing patient well-being and likely service use, it might be helpful if more information were stratified by phase (especially service utilisation).

There is little the project staff can do about the above limitations, as they relate to the construction of the software. Other limitations of the program can be overcome, but it is not clear that the project is taking advantage of these opportunities to improve the quality of the management information available. For example, there are no graphing facilities in PalCIS, but the tabular data of the service utilisation report (see Figure 5) can be pasted into (say) Microsoft Excel and graphed using its facilities. Routinely pasting summary information into a spreadsheet may also be a way of building up a longitudinal picture, thereby overcoming the predominantly cross-sectional statistics contained in the standard reports.

Figure 4 Example of univariate presentation of information from the Deaths Summary report



Figure 5 Example of the standard service utilisation report



6.5 The importance of collecting data at the episode of care level

A critical issue to be addressed when analysing data collected in the community setting relates to defining the start and end points of health care activity. To achieve this, it is necessary firstly to agree on 'units of counting' for activities or services. In theory, the unit of counting can be anything from an individual occasion of service through to episodes of illness lasting for several months or years.

The typical unit of counting in health care is the 'episode of care'. This is relatively easy to apply in inpatient settings because admission and discharge dates serve as episode boundaries and episodes tend to be of a short duration.

In the community setting, however, episodes of care frequently extend over much longer periods. As a consequence, the process of defining an episode of care is more complex. It is not practical, for example, to wait several months or years (when a patient stops receiving care) to obtain data on the range of services that were provided to that patient.

It is much more likely that information that is useful for clinical management and research purposes will be obtained if an episode of care definition is based around data that can be collected on a regular basis. At the same time, it is clearly important to ensure that any additional data collection requirements do not place too great a burden on staff.

In the community palliative care context, two useful data collection protocols are particularly relevant. The first relates to the use of the clinical tool 'phase of care'. Palliative care phase is a clinical tool that measures a patient's stage of illness. It comprises five stages: stable, unstable, deteriorating, terminal and bereaved. Definitions of each phase are provided at Appendix 4. In addition, a Palliative Care Phase Change Validation Flowchart has been developed more recently to assist in the application of the tool. A copy of this is provided at Appendix 5. When used in conjunction with the published definitions of each phase, the flowchart provides clinicians with a systematic method of correctly assigning palliative care phases.

Several recent studies have shown that change in palliative care phase is a useful method of defining community palliative care episodes. The AN-SNAP casemix classification, (Eagar et al, 1997) for example, uses change in palliative care phase as a trigger for ending the episode of care and grouping the new episode to a different casemix class²².

An important point needs to be emphasised here. It is that the unit of counting underpinning the data collection in this study needs to be the **episode of care** - initiated by a change in palliative care phase. It is critical therefore that a complete clinical profile is obtained on each patient at the beginning and end of each episode of care. That is, clinical variables need to be collected each time a change in phase of care occurs. This will allow a systematic data analysis based on a consistently applied definition of episode of care to occur. An additional benefit of this approach is that it will allow each episode of care to be assigned to an AN-SNAP class. For this reason, it is strongly recommended that all clinical variables being collected in the study be collected each time a phase change occurs. A list of these items is included in section 6.7.

The second data collection protocol applies in instances where a phase change does not occur for more than 90 days. In these cases, it is recommended that a new episode is artificially introduced for each 90 day period during which a patient is in care and the phase does not change. The rationale for this protocol is to avoid having to rely on a phase change to obtain clinical information whilst ensuring that the episode of care is used as the primary unit of counting. Again, this will

²² Eagar, K. (1997). "Defining an Episode of Care: a study of five Case Types." *Australian Health Review*, 20(3): pp.105-119.

allow a systematic data analysis based on a consistently applied definition of episode of care to occur. For this reason, it is strongly recommended that the clinical variables listed in section 6.7 are collected on each patient for each 90 days period during which a phase change does not occur.

6.6 Comments on the Griffith information system

This examination of the Griffith information system has focussed on its primary component - the PalCIS PC and Palm-Pilot system used by the project coordinator and clinical staff to collect client information, both with respect to their well-being and their service use. It has not examined the data collected with respect to the 24-hour on call service. This information is collected in another standalone database and could not be made available to the evaluation team in time for this report.

In relation to the day-to-day care of clients, either directly or indirectly (case conferences), the PalCIS system seems to meet the clinical needs of the project. As noted above, PalCIS can provide a longitudinal picture of a person's health assessment scores, and service use, and does this in a way that is readily interpreted by a clinician. It also seems to support the sharing of data among health professionals, something of key importance for a project aiming to improve care coordination.

Much of the clinical benefit of the PalCIS system comes from the comprehensiveness of its data items. It seems to cover all necessary demographic items, and includes relevant and complementary measures of the health status. The only area in which it is lacking is in the recording of service use. There are two important issues in this regard. First, the system only allows some types of service use to be captured on an event basis. In other cases, it is only possible to enter data as a weekly summary. This limitation probably stems from the system's orientation towards clinical care, but it is a serious limitation nonetheless. From a managerial (and evaluation) perspective, the information can only support decision making if resource use can be understood in terms of similar types of patients. As a minimum, this means being able to analyse service use by phase. The collection of service data on a weekly basis prevents this from being done accurately.

Second, the system does not support the collection of data about all services of interest to the project. In particular, there seems to be no facility to collect information about the use of emergency services. A key motivation for the project was the belief that palliative care patients attended emergency departments inappropriately (especially after office hours) because it was the easiest way to access care. The inability to collect data on client's attending emergency departments therefore limits the ability of the project, and others, to evaluate its impact.

Another area that the PalCIS system falls short of the ideal is in its reporting facilities. Again, this may stem from its clinical orientation. The facilities for monitoring the progress of an individual client are well-designed. This is not the case for its aggregate reports, as noted in Section 6.4. Several ways of improving the reports were discussed in Section 6.4, primarily, the need to report information by phase, and a move away from reporting data for one variable only to reporting data on two or more related variables. Other options include producing reports in the form of the tables and graphs used in Section 6.3.

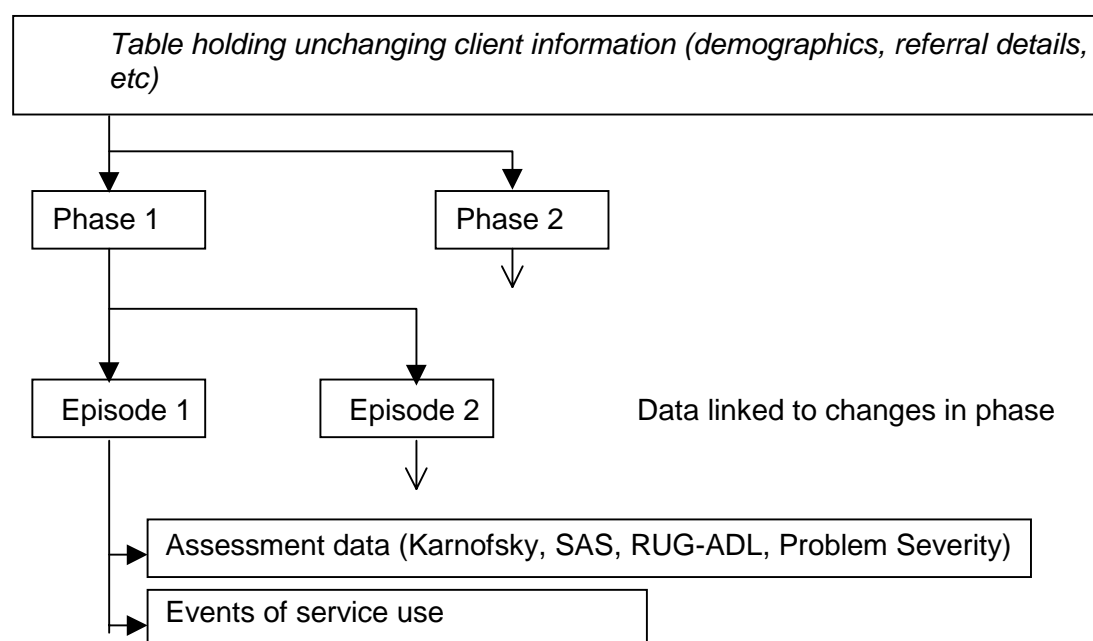
The problem for the project is that PalCIS cannot produce reports in this format. The ad hoc reporting facilities can produce some custom reports, but these appear to be of limited value. For example, in relation to analysing data by phase, this can only be done using a client's current phase, and not by the phase when an event or assessment score was recorded. For this report, it was necessary to access the underlying data tables in Microsoft Access, and manipulate the data in either Access or Excel. Whether anyone in the trial has the time and ability to do this is doubtful. The project coordinator is aware of these difficulties.

The reason why PalCIS is limited in its aggregate reporting facilities appears to be related to its data structure. Tables related to health assessment data are linked to the client table, with phase being a field in each table. Tables holding service use data are similarly linked to the client table. To support data analyses by phase, a hierarchical structure is required as illustrated in Figure 6. It would also force data to be entered consistently; the multiple fields containing the phase raise the potential for mistakes to be made.

Another beneficial consequence of adopting a hierarchical structure would be in relation to the collection of data to support the allocation of clients to AN-SNAP classes. To assign a client to a class, data on the RUG-ADL and Problem Severity index need to be collected whenever a phase changes. At present, the PalCIS system does not have a mechanism to enforce this data requirement. With a hierarchical data structure, it would be relatively easy.

Adopting a hierarchical data structure would also affect the current method used by PalCIS to capture service utilisation data. A table of weekly service use becomes inconsistent with this structure as phases may change within a week. The use of services would need to be entered as events at particular points in time, otherwise they cannot be assigned to a phase. In our view, this would be another benefit.

Figure 6 A hierarchical data structure that would support the analysis of data by phase



It is asking a great deal for the developers of PalCIS to change the data structure of PalCIS. Not only would the data structure have to change, but the design of some screens would also need to be refined. But it is our opinion that the system will only gain wider support amongst managers and government agencies if this happens. Regardless of whether this occurs, it is strongly recommended that the data items listed in Section 6.7 are collected each time a phase change occurs.

Final comments on the Griffith information system concern the completeness of the data collected, and when they are collected. The data provided to the trial appeared incomplete in a number of ways:

- service data did not contain all episodes of inpatient care, either at the time of death, or at other times;

- some clients did not have any assessment data, even though they had been in the trial for a considerable time;
- not all forms of assessment data were collected at the same time, though this might not be a serious oversight;
- the RUG-ADL and Problem Severity scores were not always collected together, or whenever there was a change in phase, so preventing the assignment of clients to AN-SNAP classes.

We understand the difficulties in implementing new data collection requirements, and would expect completeness to improve over time. There are though two points worth stressing. First, we recommend that clients be assessed at least every 90 days. This is necessary in relation to the AN-SNAP variables to allow class assignment, but it is probably also good practice to ensure clients are monitored. Second, we recommend greater effort be made to capture episodes of hospital care (inpatient, outpatient and visits to emergency departments) as these are linked to considerable resource use, and therefore cost, and the performance indicators of the project.

6.7 Summary of recommendations

1. GAPS needs to collect information based on episodes of care to make the data analysis sensible.
2. That means clients need to be assessed every time a phase change occurs, or every 90 day period during which there is no change in phase. The client assessment should include the collection of the following data items:
 - Palliative care phase
 - Phase begin date
 - Phase end date
 - RUG-ADL score – phase start
 - RUG-ADL score – phase end
 - Staff discipline
 - Palliative Severity Score phase start:
 - Pain
 - Other symptom
 - Psychological/spiritual
 - Family/carer
3. The project also needs to capture episodes of hospital care (inpatient, outpatient and visits to emergency departments).
4. In doing so, this will also allow us to assign episodes to AN-SNAP classes. This is really a bonus at this stage as the system is not yet widely in use in the project's service environment. The key objective is to get collect data based on episodes of care consistently defined and that lend themselves to being analysed.
5. Consideration be given to modifying the data structure of PalCIS to support the analysis of data by phase.

Appendix 1 **Analysis of performance indicators and targets developed by GAPS during the planning phase**

This appendix describes the reporting framework developed under the NSW Health program environment that supports the State-funded element of GAPS. It outlines the issues raised by the State-level/Area approach to accountability and contrasts the table of performance indicators and targets (key performance indicators or KPIs) with an approach that is more useful for the purposes of regular reporting, as well as evaluation.

The landscape table (Table 19) contains the performance indicators and targets developed by GAPS during the planning phase, along with an additional 'comments' column added by the evaluators. The Area Program Summary is a description of GAPS in terms of the indicators and targets for the NSW Health Chronic and Complex Care Program, and is evidence of how GAPS fits within the program.

This integration within the mainstream of the NSW health system is an important source of legitimacy and credibility for the project within the Area (GMAHS) and with the State-level program managers. It also poses some problems since it cannot be safely assumed that the mainstream initiatives are either well-planned or even sensible. The table of indicators and targets developed by GAPS in the planning phase is good evidence of the problem in that it is too complex.

Ironically, the complex and chronic care program has potential for further fragmenting service provision in the name of integration (illustrating Leutz's law²³: "your integration is my fragmentation"). This is because it is an artefact of the Government Action Plan and its huge number of committees, rather than a coherent policy initiative. In terms of integration and the encouragement of integrative models, 'complex and chronic care' is just another variant on vertical integration and attempts at imposing specialist models of primary care activities. It likely that instituting a formal program structure will get in the way of better planning in the long term, leading to further fragmentation. The difficulties will emerge with the likely attempt at the partitioning of existing programs. Acute geriatrics, rehabilitation and disability might not fit, and the advent of yet another "new" program covering a mixed collection of existing activities with unclear logic, may leave palliative care and its related services with an even more confusing administrative environment.

The following program summary shows how GAPS currently fits into the Area schema as shaped by the channel through which the funds for the State component of the project came – ie. Chronic and Complex Care.

Area Program Summary - Integrated Palliative Care:

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;

²³ Leutz, W. (1999), 'Five Laws for Integrating Medical and Social Services: Lessons from the United States and United Kingdom', *The Milbank Quarterly*, 77(1): 77-110.

- 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.

These program elements all have a capacity to be reported in terms of the chronic and complex care program's framework of performance indicators. However, the list of indicators (Table 19) is long (about 50 items) and somewhat unwieldy, and largely duplicates what is included in the evaluation framework. A more economical approach might be to eventually seek agreement between the project and the program managers at Area-level to settle on a smaller number of more useful indicators to answer the critical questions outlined below:

QUESTION	INFORMATION REQUIRED
<u>Who</u> receives	Demographic and clinical characteristics of service consumers, using a more carefully defined set of classes determined by palliative care phase
... <u>what</u> services...	Services provided, with some scope increased to cover pastoral care, counseling and perhaps HACC-type services
... from <u>whom</u> ...	Service characteristics, including 'Service Type', including hospital services
... at <u>what</u> cost...	Health resource data
... with <u>what</u> effect?	Consumer outcome data

- Refinement of the current activity definitions and improved collection of data is required to answer the second question.
- When that is in place, the first 3 pieces of the schema can be used to cost all the services including hospital, community health and community care. The current evaluation plan includes a small number of cost studies to demonstrate how this information can be linked to outcomes. In the absence of the required routinely collected AN-SNAP data, the analysis will be limited to case studies and consequently the estimates of costs will be limited (i.e. not comprehensive) and the results will be more illustrative than definitive.
- The first 3 questions are necessary for outcome measurement and the implementation of routine ways to answer them will significantly improve the capacity to measure outcomes. In palliative care the 'Consumer Types' are defined by phase, which represents the goal of care and these goals form the natural framework for outcome measurement (e.g., what was the client's outcome relative to the goal we set out to achieve?)
- The fourth question is about 'at what cost?' and a casemix-style classification of palliative care episodes is essential to answering the question. Health resource data, when assembled into a data base with cost data, allows us to confidently attribute costs, and more importantly, to predict them. This type of detailed cost modeling, using benchmark costs derived from studies of a larger population, is essential to the understanding of the issues of sustainability of the model.

Table 19 Performance indicators and targets developed by GAPS during the planning phase, with comments

Objectives	Indicators	Targets	Data Sources	Comments
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	Appendix 3 shows diagnoses GMAHS data still to be examined
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	53 patients have had 825 GP attendances. 58 GP case conferences billed. 14 patients used 106 hosp bed days 22 patients had 323 hours home nsg
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	HACC data not separately reported Data base for on-call log SNAP not implemented
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;	↑ 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	58 case conferences; other items available but not claimed protocols in place audit planned SNAP not in place Protocols in

Objectives	Indicators	Targets	Data Sources	Comments
	Strategies to ensure appropriate referral of patients to palliative care services in place; and Strategies to ensure rapid access to specialist services in place.		referrals received Time between referral and first contact Time between first contact and admission Time between referral and multidisciplinary case review Service evaluation report provided by external consultants	place No waiting time No waiting time Two completed
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	Few allied health. Psychosocial services largely absent
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	All in place IT developments under way
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	Protocols in place and new practices developing
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	Review and evaluation of community alternatives ↓ waiting time for services	Service evaluation report provided by external consultants Local service evaluation	No waiting time

Objectives	Indicators	Targets	Data Sources	Comments
	community health and community care services.		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	PaICIS data on symptom scores - more detailed analysis over longer time
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	PaICIS has symptom scores, more detail and other methods needed
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	Not known - interviews planned
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	Record audit planned, based on first 54 patients 1800 number in place
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	All part of ongoing independent evaluation

Objectives	Indicators	Targets	Data Sources	Comments
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	Record audit and area data still to be reviewed
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	Interviews to look at knowledge awareness and satisfaction in next stage
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	Preliminary results appear promising AN-SNAP not implemented
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	No waiting time Trial population is too small for sub-groups
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	Data available to demonstrate these targets achieved

Objectives	Indicators	Targets	Data Sources	Comments
			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		Governance structure in place Interviews with consumers still to be done
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	All in place
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	All in place
Has there been a shift in resources from the hospital to the community setting as a consequence of the Program?	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	Yes, pooled resources

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 promotion²⁴

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 project on these indicators was completed after all the evidence was considered.

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

2 = yes, fully
1 = yes, in part

0 = no
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. There may be differing opinions on that matter.

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 related to elements of the model and the context on which the project evaluation to date has insufficient (ie some, though still 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).

Items 7, 10 and 11 have been judged to shown positive improvements on the basis of agreements about area planning, representation on committees and more evidence for the project's visibility. These gains will be consolidated by the recommendations for accumulating more and better-reported data. The overall score at June 2002 (ie 9 months in) was 24 out of a possible 28. The total score means little in itself, but the noteworthy items can trigger debate that is formative for the project and give areas for priority attention by program management.

²⁴ 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 20 Sustainability Assessment at the Mid Point

The first set of items is about program design and implementation factors.				
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
4. 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 which are known to relate to the survival of a program				
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. Heavy borders show those items that have changed from the baseline assessment.

TOTAL SCORE: 24 (maximum possible is 28)

Appendix 3 Diagnoses of GAPS patients recorded in PalCIS

Diagnosis	Total (Primary)	%	Total (Overall)	%
Breast (female), NOS (C509)	4	7.69%	4	7.69%
Unknown 0	3	5.77%	3	5.77%
Carcinoma in situ of breast, unspecified (D05.9)	1	1.92%	2	3.85%
Liver (C220)	2	3.85%	2	3.85%
Malignant neoplasm of middle lobe, bronchus or lung (C34.2)	2	3.85%	2	3.85%
Parietal lobe (C713)	2	3.85%	2	3.85%
Motor neuron disease (G12.2)	2	3.85%	2	3.85%
Malignant neoplasm of bronchus or lung, unspecified (C34.9)	2	3.85%	2	3.85%
Malignant neoplasm of prostate (C61)	2	3.85%	2	3.85%
Non-Hodgkin's lymphoma, unspecified type (C85.9)	2	3.85%	2	3.85%
Multiple sclerosis (G35)	2	3.85%	2	3.85%
Fracture of intertrochanteric section of femur (S72.11)	0	0.00%	1	1.92%
Huntington's disease (G10)	1	1.92%	1	1.92%
Hypothyroidism, unspecified (E03.9)	0	0.00%	1	1.92%
Liver cell carcinoma (C22.0)	1	1.92%	1	1.92%
Fracture of shaft of humerus (S42.3)	1	1.92%	1	1.92%
Emphysema, unspecified (J43.9)	0	0.00%	1	1.92%
Lung, NOS (C349)	1	1.92%	1	1.92%
Decubitus ulcer (I89)	0	0.00%	1	
Colon, ol (C188)	1	1.92%	1	1.92%
Colon, NOS (C189)	1	1.92%	1	1.92%
Coeliac disease (K90.0)	0	0.00%	1	1.92%
Carcinoma in situ of stomach (D00.2)	1	1.92%	1	1.92%
Carcinoma in situ of oesophagus (D00.1)	1	1.92%	1	1.92%
Brain, other parts, ol (C718)	1	1.92%	1	1.92%
Diffuse non-Hodgkin's lymphoma, unspecified (C83.9)	1	1.92%	1	1.92%
Multiple myeloma, in remission (C90.01)	1	1.92%	1	1.92%
Thymus (C379)	1	1.92%	1	1.92%
Systemic involvement of connective tissue, unspecified (M35.9)	1	1.92%	1	1.92%
Skin, NOS (C449)	1	1.92%	1	1.92%
Secondary and unspecified malignant neoplasm of lymph node, unspecified (C77.9)	0	0.00%	1	1.92%
Prostate 0	1	1.92%	1	1.92%
Pancreas, tail (C252)	1	1.92%	1	1.92%
Pancreas, NOS (C259)	1	1.92%	1	1.92%
Malignant neoplasm of colon, unspecified part (C18.9)	1	1.92%	1	1.92%
Multiple myeloma, without mention of remission (C90.00)	1	1.92%	1	1.92%
Lymphoblastic (diffuse) non-Hodgkin's lymphoma (C83.5)	1	1.92%	1	1.92%
Malignant neoplasm of uterus, part unspecified (C55)	1		1	1.92%
Malignant neoplasm of oesophagus, unspecified (C15.9)	1	1.92%	1	1.92%
Malignant neoplasm of head of pancreas (C25.0)	1	1.92%	1	1.92%
Malignant neoplasm of hard palate (C05.0)	1	1.92%	1	1.92%
Malignant neoplasm of gallbladder (C23)	1	1.92%	1	1.92%
Bone marrow (C421)	1	1.92%	1	1.92%
Malignant neoplasm of body of pancreas (C25.1)	1	1.92%	1	1.92%
Oesophagus, lower third (C155)	1	1.92%	1	1.92%

Appendix 4 Palliative Care - Definitions of 'Episode of Care' and 'Phases of Care'

Palliative Care Episode Definition

An episode of palliative care is:

- provided for a person with an active, progressive, far advanced disease with little or no prospect of cure, and
- for whom the primary treatment goal is quality of life
- which is evidenced by:
 - + multidisciplinary assessment and/or management of the physical, psychological, emotional and spiritual needs of the person
 - + a grief and bereavement process for the person and their carers/family

Inclusions:

- A palliative care provided in both community and hospital settings
- B grief and bereavement support services for the family and carers during the life of the person and continuing after death.

Palliative Care Phase Definitions

(1) Stable Phase

- All clients not classified as unstable, deteriorating, or terminal
- The person's symptoms are adequately controlled by established management.
- Further interventions to maintain symptom control and quality of life have been planned.
- The situation of the family/carers is relatively stable and no new issues are apparent. Any needs are met by the established plan of care.

(2) Unstable Phase

- The person experiences the development of a new problem or a rapid increase in the severity of existing problems, either of which require an urgent change in management or emergency treatment
- The family/carers experience a sudden change in their situation requiring urgent intervention by members of the multidisciplinary team.

(3) Deteriorating Phase

- The person experiences a gradual worsening of existing symptoms or the development of new but expected problems. These require the application of specific plans of care and regular review but not urgent or emergency treatment.
- The family/carers experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the person. This requires a planned support program and counselling as necessary.

(4) Terminal Care Phase

Death is likely in a matter of days and no acute intervention is planned or required. The typical features of a person in this phase may include the following:

- Profoundly weak
- Essentially bed bound
- Drowsy for extended periods
- Disoriented for time and has a severely limited attention span
- Increasingly disinterested in food and drink
- Finding it difficult to swallow medication.

This requires the use of frequent, usually daily, interventions aimed at physical, emotional and spiritual issues.

- The family/carers recognise that death is imminent and care is focussed on emotional and spiritual issues as a prelude to bereavement.

(5) Bereaved Phase

Death of the patient has occurred and the carers are grieving. A planned bereavement support program is available including counselling as necessary.

Appendix 5 Palliative Care Phase Change Validation Flowchart

