

About this report

The Centre for Health Service Development was commissioned to evaluate the *Griffith Area Palliative Care Service (GAPS)* project. This is the last in a series of three 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 second report covered the changes implemented in the delivery of palliative care services over the first nine months of the project. This final report describes the achievements of the project after 18 months. The project will continue after this report, being expanded to populations that are more distant from the population centre of Griffith, and is expected to become progressively mainstream within the Greater Murray Area Health Service.

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The three reports in this evaluation series are:

Owen A, Perkins D, Senior K and Eagar K (2001) *The Griffith Area Palliative Care Service: a baseline assessment of its evaluability, sustainability and generalisability*. Centre for Health Service Development, University of Wollongong

Owen A, Perkins D, Senior K, Cromwell D, Eagar K and Gordon R (2002) *The Griffith Area Palliative Care Service: Second Evaluation Report*. Centre for Health Service Development, University of Wollongong.

Cromwell D, Senior K, Owen A, Gordon R, and Eagar K (2003) *Can the National Palliative Care Strategy be Translated into a Model of Care that works for Rural Australia? An Answer from the Griffith Area Palliative Care Service (GAPS) Experience*. Centre for Health Service Development, University of Wollongong

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Executive Summary

Background

In October 2001, health services in Griffith, New South Wales, began a project to improve access to, and the integration of, local palliative care services. The Griffith Area Palliative Care Service (GAPS) project was funded as a national demonstration project with support from the Commonwealth and State governments and the Greater Murray Area Health Service. One motivation for the project was the recognition of various weaknesses in the organisation of services in Griffith. But another, broader, aim was to assess how the National Palliative Care Strategy could be translated into a model of care that is appropriate for rural Australia.

This report describes an evaluation of the GAPS project from October 2001 to March 2003. It is the third in a series of reports, the earlier ones providing baseline and a mid-term perspective. The evaluation used a mix of quantitative and qualitative methods to describe the impact of the new model of care on patients, carers and clinical staff involved in the project.

The GAPS model of care grew out of a partnership between Griffith Base Hospital, Murrumbidgee Division of General Practice (MDGP) and the Griffith Community Health Centre. Considerable time was spent planning the project prior to it being funded, and the above stakeholders were joined by the (private sector) Griffith Nursing Services, Griffith Ministers Fraternal and the Griffith Volunteer Support Group as partners in the project. The project aimed locally to improve palliative care services for residents in the Griffith region (Western Riverina), starting in Griffith (approx 20000 residents) and later being extended to residents in the surrounding areas of Coleambally, Darlington Point, Hay and Hillston. At a broader level, the project aimed to develop a model of care that could be appropriate for other rural communities.

The generalist model of service delivery was built around various elements, the most important being:

- The adoption of common referral criteria for palliative services to improve access, including access for people with non-malignant conditions;
- The adoption of weekly, one hour case conference meetings involving GPs, community nurses, staff from the Griffith Base Hospital oncology/palliative care unit;
- The establishment of a 1800 number, and an on-call nursing roster, to provide 24 hour, 7 days access to palliative care services;
- Local GPs being given VMO arrangements at Griffith hospital to allow them to attend their palliative patients if they present to the emergency department or are admitted;
- The adoption of shared service protocols that promote continuity of care;
- The creation of a patient-held record so that the patient, their carers and each service provider understands the contribution of each provider and the care that is required;
- The implementation of an computer information system that enables richer patient data to be stored and analysed, and that facilitates a more consistent approach to patient assessment;
- Expanded professional education for staff; and
- The employment of a project coordinator; and
- The creation of a Board of Governance to oversee the development and running of the project.

The project had made considerable progress in implementing these elements by June 2002 (described in detail in the mid-term evaluation report). 52 patients had been enrolled by that time, of whom 27 had died. The initiatives to improve service access and coordination were viewed very positively by clinicians and stakeholders. The case conferences were successful in improving communication and there had been a general acceptance of arrangements for shared care. The 1800-number and on-call nursing roster were providing improved quality of care, and a safety net for patients and carers. Fewer patients were believed to be visiting the hospital emergency department seeking after-hours care. Overall, the cultural change for service providers was being managed effectively, and the project coordinator, with the Board of Governance, was providing the project with strong leadership.

The project continued to develop after June 2002, making various changes to how palliative care was organised. There was a significant change in the way that domiciliary nursing for the GAPS project was organised. Initially, day-time home visits to GAPS patients were made by a combination of community nurses and the nurses from the hospital oncology unit, but the community nurses were later assigned as primary case workers for domiciliary patients. The oncology nurses no longer undertook day time visits and instead concentrated on their hospital based work and developing the GAPS service for outlying areas. GAPS initially expanded to cover Coleambally (11 Sept 2002) being followed by Darlington Point and Hillston.

Scope of project and patient demand

Ninety five patients were referred to the GAPS program between October 2001 and March 2003. Between 20 and 35 patients are enrolled with the project at any one time. This was significantly more than the 10 patients in need of palliative care at any one time that people thought were in Griffith at the outset of the project. This discrepancy is likely to be due to several factors. First, it seems that under GAPS, patients are designated as palliative at an earlier stage and so remain under the care of services for longer. Second, the scope of the project was deliberately expanded to ensure patients with non-malignant conditions had access to palliative care services. The latter is consistent with national policy guidelines.

Improvements in quality of care to patients

The GAPS program has clearly had a positive impact on the quality of care experienced by the people of Griffith. Patients are no longer presented with a fragmented organisation of services and variable after-hours coverage. The implementation of the 1800-number and on-call nurse roster means that services can be accessed on a 24-hour, 7-day basis. This provides patients with a safety-net, and the project perceives that this has resulted in fewer inappropriate attendances at the Griffith Base Hospital emergency department. This is an important improvement as patient emergencies are recognised as a problematic part of providing predominantly home-based care.

Continuity of care has also been enhanced with the adoption of shared protocols, the patient-held record, the provision of VMO rights at Griffith hospital to GPs treating palliative care patients, and the multi-disciplinary approach to care and case management.

Patients and carers considered that the patient held record had led to beneficial changes in the way that care was organised. In particular, emergency trips to the hospital had previously involved long waits and unnecessary tests. Being able to show the records has made such visits less stressful as medical staff now know the patient's history.

The program recognises that progress can be made in several areas. To date, there has been only limited incorporation of non-medical aspects of palliative care into procedures, notably, pastoral care. Access to bereavement support for families and friends has also remained problematic, although this issue is not solely in the sphere of GAPS to solve, being linked to a shortage of staff in the Area generally. There is also a perception among patients that the

community nurses have heavy workloads and this has resulted in a certain reluctance to use the 1800-number after hours.

Changes in service organisation

The GAPS model of care required a number of changes in service organisation and greater cooperation across services. GPs were given VMO rights to the hospital for their palliative care patients, and the Murrumbidgee Division organised a GP on-call roster. The community nursing staff and oncology nurses also shared the duties on the new on-call roster that supported the 1800-number. This was organised by the Greater Murray Area Health Service (GMAHS). A number of shared care protocols and policies have been adopted.

The weekly, one hour case conferences (attended by GPs, Area clinical staff, private nursing services and a pastoral care representative) have proved to be an effective forum for organising treatments and problem solving. It has also provided staff with a support structure and stimulated greater understanding across professional disciplines. Most GPs believe that the new EPC items are an effective way of financing the meetings and attendance by all staff has been good.

The nurses undertaking the home visits adopted a number of new strategies, most of which appeared to be effective and not burdensome. The patient held record seemed to be meticulously updated, which allowed for a smooth transition between service providers. Most GPs also reported entering data into the patient held record and thought it useful, although a few rated the records as being only moderately accurate. The nurses adopted several measures of health status including the Karnofsky scale (a measure of symptom severity) and the RUG-ADL (a measure of functional status). These were thought to aid an objective discussion about the well-being of a patient, and helped with understanding the patient history. However, the use of Palm-pilots to enter this patient data into a computer at the point of care was not universally liked, and was not widely used. Because this resulted in incomplete data being collected, the potential of this type of computer support remains unproven.

The project has made less progress against some other objectives. Support for staff after the death of a patient is still informal, and access to education material and opportunities remains limited. This is partly exacerbated by a lack of computers among nursing staff in both the community health centre and the oncology unit. Access to the Internet would be a useful source of clinical information (as well as management/policy documents) and email would support communication generally.

A final issue was raised by the re-organisation of home nursing visits that occurred mid-way through the project. These had previously been shared between community nurses and staff at the oncology unit, but later these were restricted to the community nurses. The service utilisation data demonstrate a reduction in nursing activity after this point, and the community nurses appeared to be stretched. Also, the oncology nurses remained on the on-call roster but were now less familiar with the patients, and their living arrangements. An important evaluation finding is that this change has not been in the best interest of either patients or staff.

Management and governance

The new model of care represented a substantial change in work practices, not only within organisations but across organisations. The local stakeholders invested considerable time and resources in planning the new model of care, and its speedy deployment demonstrates the quality of these efforts. The creation of a suitable management structure, with the appointment of a project coordinator and a Board of Governance, were also important developments. Both made major contributions to the implementation of the model. The coordinator role encompassed a number of activities, including project design and development, project management and liaison with health care and volunteer services. The project was fortunate to find an experienced palliative care nurse to take on this position.

This structure provided the project with sufficient autonomy to develop a model of care suitable for the local context, but which differed from other models within the Area. The project had high-level support within the GMAHS to pursue this agenda, but apart from a representative of the Area sitting on the Board of Governance, links to other palliative care services within the Area were limited. The relationship between GAPS and the Mercy Hospital in Albury, which is responsible for developing Area-policy on palliative care, was minimal. Although some nurses initially sought support from the Mercy services, a stronger relationship between GAPS and the Mercy hospital was not pursued at a project-level. While understandable in the early stages of the project, given the internal changes to be implemented, the project perhaps missed an opportunity to tap into a source of expertise by not establishing a formal link. Instead, the project developed links with the South West Sydney palliative care service. While this has been a good local solution, it is not the best arrangement from a system perspective.

Sustainability

The GAPS project has been successful in generating a high level of support and enthusiasm on the part of the staff involved and the general community. The implementation of the project was well funded by both State and Commonwealth, and the essential elements of GAPS require little recurrent funding. The project coordinator played an important role in the implementation of GAPS, but funding for the position is not ongoing and GAPS will have to adapt to functioning with a reduced coordinator role. As the major changes have already been established and other members of the GAPS team have gained considerable knowledge and experience, this should be achievable.

The potential for sustainability would be enhanced by the management of GAPS becoming more embedded in existing management structures such as the Area Health Service. It will also be necessary for GAPS to develop and maintain relationships with other palliative care services in the region, with a long term goal of palliative care services being coordinated on an Area wide basis.

The high demands that GAPS currently places on nursing staff are a serious threat to the long term sustainability of the project. It is necessary to increase the number of nurses available to do home visits, in order to provide patients with quality care and reduce the existing workload and subsequent exhaustion and burnout of the nursing staff.

Generalisability

The GAPS model of care appears to be appropriate for towns of a similar size and with similar resources to Griffith (a dozen GPs, regional hospital and community services). The extension of the model to the regional towns around Griffith has shown that the service can be successfully implemented in smaller areas, if they can be supported by the services of a larger area.

In areas with larger populations, the GAPS model becomes more problematic, perhaps requiring the population to be split into zones. Furthermore areas with larger populations may be in the position to offer alternative patterns of care, not least using specialist palliative services through their hospitals. Incentives for GPs to be involved in such a program may also vary from one area to another.

A serious concern arises in the potential cost to patients of a primary care led service such as GAPS. Patients treated by a service based on general practice face the prospect of paying co-payments (for privately provided medical, diagnostic and pharmaceutical services) in contrast to public patients of a specialist palliative care service who are unlikely to face such co-payments.

That said, a specialist palliative care service is not a realistic option for small, dispersed communities. The GAPS model, with its primary care and multidisciplinary approach, is a quality alternative.

1. Introduction

In October 2001, a new model of palliative care was implemented by health services in Griffith, New South Wales. The project was funded as a national demonstration project with support from the Commonwealth and State governments, and Greater Murray Area Health Service. One motivation for the project was the recognition of various weaknesses in the organisation of services in Griffith. Thus, one of the primary aims of the project was to improve access to, and the quality of, the local palliative care service. But another, broader, aim was to assess how the National Palliative Care Strategy could be translated into a model of care that is appropriate for rural Australia.

The Centre for Health Service Development was commissioned to evaluate the Griffith Area Palliative Care Service (GAPS) project. This report relates to the third and final part of the evaluation, and describes the progress of the project up to March 2003. An initial evaluation report provided an account of the background to the study and the period of planning and initial live phase up to December 2001. The second evaluation report examined the progress that the project had made up to August 2002. In this third report, we examine various aspects of the project including:

- The health status of patients on referral and progress through the project;
- Patterns of service delivery;
- Reactions of patients and staff to the model of care; and
- Management and governance structures of the project.

At a broader level, the evaluation addresses strategic issues related to the National Palliative Care Strategy. These concern whether the model of care is both sustainable, and whether the model is generalisable to other rural settings.

1.1 *Outline of evaluation methods and data sources*

The evaluation team adopted a mix of quantitative and qualitative methods for the evaluation. To describe the impact of the model of care on patients, carers and staff, the dominant approach was qualitative. Over the duration of the project, interviews were held with staff at various points to collect information on how the project was progressing. This was then supplemented with a three-week period of ethnographic research in which a researcher accompanied staff as they undertook their work, and (if they consented) spoke to patients and carers about their experience of the condition and care.

The evaluation also examined quantitative data on the characteristics of patients (condition, rated health status) and their associated service patterns. This analysis was primarily based on data collected within the computer-based information system being tested by the project, but it was also supplemented by data that were held on paper-based records.

The final aspect of the evaluation concerned the management and governance structures of the project, and its interaction with other services and stakeholders. Again, the primary approach to evaluation was qualitative, being based on interviews with those involved and on observations made by researchers attending meetings (either in person or via a teleconference link).

Ethics approval for the evaluation was obtained from the University of Wollongong Ethics Committee.

2. An overview of palliative care

This chapter provides a background to the role of palliative care services within a health care system. Our intention is to outline the theoretical framework and Australian context within which the GAPS project fits. The chapter is not intended to provide a systematic review of the literature on palliative care, examples of which can be found elsewhere [Hearn and Higginson, 1998; Wilkinson et al., 1999; Franks et al., 2000].

Palliative care is generally understood to be care “provided for a person with an active, progressive, advanced disease who has little or no prospect of cure, and for whom the primary treatment goal is quality of life” [PCA, 1999]. It refers to activities which aim to ameliorate the effects of progressive, terminal illness, and improve the quality of life of the patient, family and friends. Important principles in palliative care are (1) the delivery of medical and other services (like pastoral care) in the environment of the person’s choice and (2) supporting the physical, psychological, emotional and spiritual needs of patients, families, friends and carers during the life of the patient and following his/her death.

Patients who require palliative care fall into three main disease groups [Franks et al., 2000]:

- Cancer;
- Non-malignant progressive disorders - circulatory, cardiovascular, cerebrovascular, respiratory, nervous system, motor-neurone disease, multiple sclerosis, dementia, AIDS/HIV;
- Children’s terminal diseases - hereditary generative disorders, muscular dystrophy, cystic fibrosis.

People with cancer constitute the majority of adult palliative care patients, being generally 85-90% of referrals [NSW Health, 2001a]. Cancer patients tend to use palliative care services in a period prior to death, but this pattern is not repeated for all types of patients [Franks et al., 2000]. In other conditions, the health status of a patient may be relatively stable but have periods in which symptoms become worse or progressive, followed by a sudden death. For example, patients with multiple sclerosis and motor neurone disease have different characteristics from cancer patients, a key issue being their long duration of symptoms. In this case, palliative care revolves around providing help in episodes of severe symptoms and providing respite care. Patients with HIV/AIDS also have different disease characteristics and palliative care needs, being characterised by periods of acute infections requiring hospitalisation as well as longer term decline.

The moment of referral to a palliative care service depends on patient characteristics, their condition, and the arrangement of services. Most patients referred to palliative services survive for up to six months, but there is considerable variation because it is often difficult to give an accurate prognosis and estimate of survival, especially for non-malignant conditions. Moreover, palliative care services such as pain management and symptom control are increasingly viewed as being relevant to patients who may not be terminal. Such people may remain “active” palliative patients for a long time.

The use of palliative care services by patients with chronic conditions, but who are not yet terminal, is one reason why demand for palliative care services is expected to increase; the scope of palliative care services is expanding. Other reasons why demand is expected to rise are (1) an ageing population and an increased life expectancy means that more people will die from cancer, and (2) the incidence of cancer is also increasing [Franks et al., 2000].

Palliative care services may be provided “at any time from the diagnosis of a condition with a limited prognosis up until and after the death of the patient” [PCA, 1999] and it is generally accepted that health organisations should adopt a flexible and holistic approach to the delivery of care so that it is unique for each individual person and family. A key principle is to allow patients

to remain at home, and provide home-based care. Many patients also prefer to die at home although the proportion of palliative care patients who actually do so is considerably lower [Grande et al., 1998]. This is partly because the burden of care becomes too great for home care to be a viable option, but there are also a variety of other reasons that determine whether or not a person is able to die in their preferred location, related to service provision or access to other levels of community support.

Palliative care is now recognised as being a specialty area requiring specific knowledge and skills [McConigley et al., 2001]. Services are required across a range of settings and stages of illness, and involve a variety of health care professionals and other carers.

Specialist palliative care services in Australia are funded primarily by individual State and Territory health authorities (under various program arrangements), supplemented by a relatively small proportion of direct Commonwealth funding (not including payments to medical practitioners under Medicare). Primary palliative care services are funded and delivered through mainstream arrangements. These include subsidies for medical services, diagnostics and pharmaceuticals through the Health Insurance Commission ('Medicare') and funding of community nursing and other services through State-funded community health services. These arrangements result in variations in palliative care organisational structures and service delivery patterns across jurisdictions, with State policies and practices being influenced by various considerations including population levels and geographical location, cultural and socio-demographic factors.

Despite the jurisdictional differences, there are many similarities in the definitional and organisational frameworks around which palliative care services are typically planned and delivered. Services are provided in inpatient, outpatient and community settings (such as a person's home or residential aged care facility) and by a mix of providers from both the public and private sectors including [NSW Health, 2001a]:

- Specialist providers: medical, nursing, allied health staff trained or experienced in palliative care;
- Generalist providers: clinicians working in other areas who have a professional involvement with patients receiving palliative care; and
- Support services: including those who assist with processes of daily living, enhancing quality of life and provide emotional and spiritual support.

The key principles of service delivery focus on culturally appropriate support for patients and carers by providing access to services that help maintain quality of life [PCA, 1999]. People should be able to move freely between settings to ensure quality and continuity of care. Other key principles are:

- To provide spiritual and cultural support to the patient, carers and family;
- To help with bereavement for both the deceased's family and service providers; and
- To provide education for patients, carers and friends, and training for service providers.

Services are encouraged to adopt an interdisciplinary team approach that includes medical, nursing, and allied health staff as well as trained volunteers (such as pastoral care workers).

Within Australia, there is broad support for these principles, which are outlined in more detail by Palliative Care Australia [1999]. Within NSW, they form the basis of the planning framework for Area Health Services. Each Area is required to develop a palliative care plan that:

- Is focussed on needs of individuals;

- Ensures support for symptom control and pain management through generalist and specialist programs;
- Provides patients and carers with 24-hour access to trained palliative care staff. Where this is not possible, appropriate triage by generalist staff (eg, by telephone) should be explored;
- Supports the development of partnerships between specialist services and general practitioners (GPs) with an expertise in palliative care;
- Ensures care/services are effectively coordinated. These links should ensure appropriate and timely referral, and coordinated discharge planning. Networks should be formalised, and flexible models of care should be explored and implemented;
- Ensures the sharing of patient information between providers.

The range of services available and specific models of care are influenced by the geographical dispersion and needs of populations. It is neither possible nor desirable to provide the same level of service in every location, and individual States and Territories have developed various systems for classifying levels of palliative care services. These are described in detail in Appendix 1; only a brief overview is provided here to outline the issues that arise in relation to the GAPS project.

Inpatient palliative care is provided either in designated hospices, palliative care units in hospitals, or in hospitals without a designated palliative ward. The demand for palliative care means that hospices are located only within larger Australian cities. Similarly, hospitals with designated palliative care services tend to be located in cities or larger regional centres. The units in city hospitals may vary in size from 30 to 50 beds, whereas those in regional centres may operate between 5 and 30 palliative care beds. In many rural and remote parts of Australia, hospitals do not have a designated palliative care service, and are supported by having access to specialist services in major cities. Medical specialists may travel to the hospital to provide services, or patients may travel to specialist inpatient units for care.

In the community sector, there are various models of care under which specialist and general clinical staff operate. Specialist medical and allied health staff are usually hospital based, and tend only to be available in metropolitan areas. In rural and remote locations, services tend to follow a generalist model in which general practitioners and generalist community nurses form the main basis of a multi-disciplinary palliative care team. The availability of specialist palliative care community nurses is also dependent upon population size, but they are not restricted to large population centres. It is not uncommon for them to be based at community health centres in rural locations. They will work closely with community generalist nurses although the role they play will differ between locations.

The medical control of symptoms and pain are not the only important dimensions of palliative care. Patients and families must attend to other aspects associated with dying, among which spiritual support is recognised as being very important. Thus, volunteer services play an important part of palliative care services, with clergy and pastoral care workers forming the group of volunteers most often involved. Charities and other voluntary agencies can also provide considerable assistance, such as help with mobility, equipment, financial advice and respite services.

Home-based care presents many challenges to both informal and formal care givers. Patients' homes, unlike institutional settings, are not designed to facilitate the care of a dying person. Home modifications and the provision of special equipment, such as hoists, commodes and hospital style beds may be necessary [O'Neill & Rodway, 1998] and informal carers must be trained in the use of such equipment. Despite modifications, carers may still have to operate in settings that are cramped and less than optimal.

Medications left in the home are another important consideration in home-based care. Carers have to be trained how to use medications, and clinicians must be confident that medications (such as morphine) left in the home will not be misused or present a risk.

Emergencies have been described as the most challenging aspects of home based palliative care [O'Neill & Rodway, 1998]. Preparation for potential emergencies requires the provision of clear advice for carers of how to recognise an emergency and who to contact in such an event.

The capacity of informal carers to provide care is an important consideration. Most informal carers have had little experience of dying people and little knowledge of what to expect. As a result caring for a dying relative (or friend) involves not only emotional strain, but a steep learning curve. In situations where there is a strong ethic that relatives will provide care at home, carers may be reluctant to disclose their concerns or ask for help, due the fear they will be seen as inadequate. Attempting to assist people who do not have the capacity to care for their relatives because they are physically and emotionally exhausted or ill themselves has been identified as an important source of stress for community nurses [Wilkes & Beale, 2001].

Finally, there is the issue of organising the effective coordination of, and communication between, services. In larger regional centres, where palliative services are organised into a dedicated unit, this can be easier than in smaller locations without this resource. Nonetheless, the separate structural arrangements for general practice and hospital/community services means that it is usually necessary to have some standard protocols and procedures to avoid patients receiving a fragmented service. In Australia, making these arrangements has become easier with the introduction of the Enhanced Primary Care items under Medicare. These support GPs taking a greater role in assessment, care coordination and to participate in multi-disciplinary care planning by providing items under which these activities can be billed.

3. Background to the Griffith Area Palliative Care Service (GAPS) project

3.1 Local context

Griffith is part of the Greater Murray Area Health Service (GMAHS), which covers a large geographical region containing an estimated 256,658 residents in 1996. There are four main areas of higher population density, namely, Wagga Wagga, Albury, Griffith and Deniliquin, but the Area covers a host of smaller towns and encompasses 29 Local Government Areas (LGAs) [GMAHS, 2002a]. Wagga Wagga and Albury are the main population centres, with the estimated number of residents living in and around these towns being respectively 55,519 and 48,630. Both towns are sites for Regional Referral Base hospitals. Another Base hospital is located at Griffith but the Area also includes another 21 community hospitals and four multi-purpose centres.

Palliative care services are organised into four sectors within the region, these being Wagga Wagga, Albury, Griffith and Deniliquin [GMAHS, 2002b]. Each sector has developed various models of service delivery that reflect their environment and resources. At an Area level, palliative services are coordinated by the private Mercy Health Service, based in Albury, under a Memorandum of Understanding with GMAHS and NSW Health. The hospital in Wagga Wagga has access to a Medical Staff Specialist Service run on an outreach basis from St Vincent's Hospital Sydney. The Mercy Hospital in Albury has a similar partnership with Melbourne based palliative care specialists. Outside these towns, service delivery is based on a generalist model that involves general practitioners, clinical nurse consultants (CNCs), community nurses and allied health professionals. Consequently, the local Divisions of General Practice have an important role to play in ensuring GPs are part of care coordination.

The Griffith Palliative Care Service covers two GMAHS health service networks: HSN1 (Western Riverina - covering Griffith, Hay, Hillston, Coleambally and Darlington point) and HSN2 (Murrumbidgee - covering Leeton, Narrandera and Barellan). The Griffith Base Hospital provides inpatient and ambulatory oncology services but, unlike Wagga Wagga and Albury, does not have a dedicated palliative care unit. The town of Griffith itself has a population of 22,296 (2001 Census), and is ethnically diverse. Over 20% of the Griffith population speak another language than English at home.

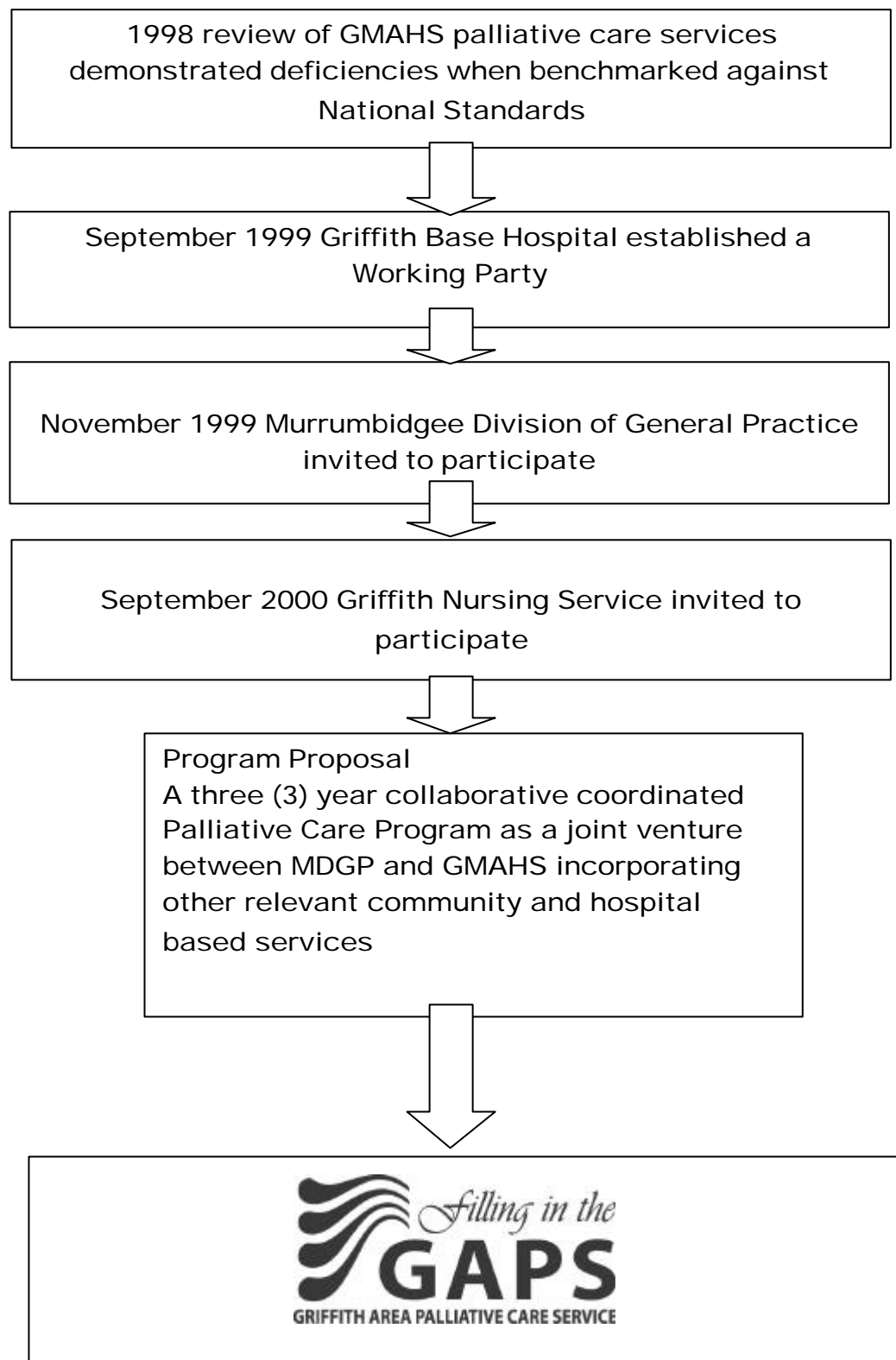
3.2 Project History: service delivery in the Griffith area

The GAPS project stemmed from a series of activities within the Area that examined the quality and organisation of palliative care. Its origin can be traced to the 1998 'Sach Report' on local palliative care services, and the subsequent steps that were taken are outlined in Figure 1.

The 'Sach Report' identified a number of weaknesses in the services provided in the Griffith area when compared with national standards. These included:

1. Access to palliative care services was problematic for non-oncological patients;
2. There was no operational link between general practitioners and community nurses;
3. There was no formal volunteer network outside that provided by the Cancer Patients Assistance Society (CPAS);
4. The collection of data on palliative patients was inadequate, failing to meet the standards required by the National Minimum Data Set.

Figure 1 *Developmental history of the GAPS project*



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

Following on from the initial report, Griffith Base Hospital established a working party to examine structures and processes in more detail using as a benchmark the Standards for Palliative Care Provision developed by Palliative Care Australia [1999]. The Murrumbidgee Division of General Practice and Griffith Private Nursing Service also participated in the review process. As well as considering alternative service delivery models, the working party identified additional weaknesses, including:

- Palliative care patients were not clearly identified - no actual medical record;
- GP involvement was variable and not coordinated;
- Specialist Palliative Care nurses were overloaded with work, including after-hours;
- Patients had no clearly defined pathway to follow for after-hours care. As a result, many attended the Griffith Base Hospital emergency department;
- Specialist services were not well coordinated;
- The role of District and Private nursing was not acknowledged;
- No core management and poor communication between services; and
- No educational/reference material was available for staff.

The burden on GPs was recognised as being high when caring for a palliative patient, especially if they had a series of such patients. Some GPs attempted to provide cover 24 hours / 7 days per week, especially in the terminal phase of an illness. Many GPs reported this to be exhausting and demanding.

The limitations of the after-hours system had a negative impact on patients. It was believed that patients often ended up at the emergency department but, because the ED medical staff could not identify a patient as palliative, patients could often have unnecessary examinations and/or be admitted to a ward under the nominated "on-call" specialist. This could disrupt continuity of care.

3.3 CHSD survey of palliative care activity before the GAPS project

The documents relating to this pre-GAPS phase do not provide quantitative figures on the number of palliative care patients that were treated within the Griffith region, and what demands they made on local services, including the emergency department. Consequently, an attempt was made to construct a baseline picture that might be useful to comparative purposes. The task was not straight forward, however, due to the fragmented nature of the services, and the limitations in the information systems at the time.

In relation to services provided by GMAHS facilities, data were potentially available from various sources. Inpatient and emergency department (ED) activity at Griffith Base Hospital are recorded routinely by HOSPAS and EDIS respectively. The difficulty was to identify which patients were palliative. Community health data are collected electronically by DOHRS but palliative care activity data could not be extracted from this system. Only paper-based community health records could be examined. Finally, nursing staff in the oncology unit kept a paper-based system on the care provided to its patients. This included records of telephone contacts, home-visits as well as outpatient activity. Data were not available on GP activity.

To identify palliative patients, it was assumed that each had been admitted once to Griffith Base Hospital, and had been flagged using the care category variable in HOSPAS. On request, hospital staff extracted all such inpatient records for the period July 1999 - June 2001, which identified 47 individuals. Then, for this group of patients, hospital staff extracted their ED attendance history from EDIS, and reviewed their community health records. Community health activity was documented using a simple form that recorded date of visit, duration, reason for visit and whether or not it was related to palliative care. The ED data were also rated for whether or not a visit was

associated with palliative care. Finally, date of death was recorded (unknown for five cases). These de-identified data were then provided to the CHSD.

Of the 47 patients, two patients died after the GAPS project had begun, and were therefore excluded from the analysis. Among the remaining 45, there were slightly more males than females (55%), and the majority were over 60 years of age (75%). Inpatient diagnosis data revealed that all but seven had a malignant disease. (It is possible that some of the remaining seven did as well but an identifying condition code was not recorded.)

It was not clear exactly when patients were considered palliative, so an estimate was made by using the earliest date that a service related to palliative care was delivered. Subtracting this date from the date of death gave an estimate of how long patients received palliative care. Across the 40 patients for whom a value could be derived, the average duration was 105 days, although the duration for 50% of patients was 73 days. Twenty-nine patients (72%) died within six months of first receiving palliative care.

The 45 patients made a total of 146 visits to the emergency department over the two year period, but only 91 visits were related to their palliative state. 11 patients made no visit. Among those that did, 15 attended once, 11 attended two or three times, while four patients attended six or more times. Of the 91 visits, 31 (34%) occurred "after-hours" (between 18:00 and 08:00). On 71 occasions, the visit resulted in the patient being admitted (although only 60 appeared among the HOSPAS data).

In relation to the use of community health services, the records of only 17 patients could be found and reviewed. Of these, four were recorded as being private patients. Only 17 of the 212 community nursing visits were regarded as non-palliative, and a total of 157 hours of palliative care were delivered over the examined period. This translates into an average 9.25 hours of care per patient but the comparative value of this figure is limited. There was considerable variation among patients in the amount of services utilised, and there were no health status data which might have helped explain this variation. Time of visit was not recorded in the community data.

In summary, the small number of pre-project patients limits the direct comparisons that can be made with GAPS activity data. But it does provide some evidence supporting the reported weaknesses with the arrangement of services prior to the project. Many visits were being made to the emergency department, and a significant proportion of these occurred after hours. The number of these visits that might have been avoided is unclear, but they provide a baseline against which later data can be compared.

4. Implementation of the GAPS model of care

4.1 The GAPS model of care

As noted in the previous chapter, the GAPS model grew out of a commitment from Griffith Base Hospital, Murrumbidgee Division of General Practice (MDGP) and the Griffith Community Health Centre to address weaknesses in their palliative care service. Considerable time was spent planning the project prior to it being funded, and the above stakeholders were joined by the (private sector) Griffith Nursing Services, Griffith Ministers Fraternal and the Griffith Volunteer Support Group as partners in the project.

The project aimed overall to improve access to palliative care services for residents in the Griffith region (HSN1 - Western Riverina) and better integrate services to improve the continuity of care. Specific objectives outlined in the project proposal, and by stakeholders when surveyed in 2001, were:

1. To provide a high quality and responsive service to patients and carers;
2. To ensure that appropriate care and expertise are available when needed;
3. To prevent the inappropriate use of services such as the emergency department when better alternatives are available;
4. To use multi-disciplinary care planning so that services are coordinated, patient problems are anticipated, and services can cater for patient preferences such as place of care;
5. To make palliative care available to all who need it within the community;
6. To improve job satisfaction for staff, by supporting their emotional needs, and better managing their workloads by sharing responsibilities.

The new model of care proposed for testing in the GAPS project involved linking a number of organisations, involving both public and private medical services within the Western Riverina region as well as volunteer organisations (see Table 2). The model would be tested first in Griffith, and later on extended to residents in the surrounding area (to Coleambally, then Darlington Point, Hay and Hillston). The resident population of the Western Riverina area is presented in Table 1.

The model was intended to evolve progressively, with staff learning from their experience within Griffith before attempting to address the more complex problems of serving more remote communities. Specific issues to be addressed included low population density and long distances, shortages of specialised staff and encouraging GP coverage and support.

Table 1 Age and Gender distribution of the Western Riverina region (HSN1)

Locality	0-14		15-29		30-44		45-64		65+		Total*		All
	M	F	M	F	M	F	M	F	M	F	M	F	
Carrathool	398	403	328	234	436	356	388	296	157	154	1713	1450	3163
Griffith	2680	2532	2421	2320	2529	2379	2186	2059	1072	1360	10918	10676	21594
Hay	482	463	381	358	425	408	432	408	200	261	1923	1901	3824
Murrumbidgee	316	302	263	214	282	253	288	245	116	105	1268	1119	2387
Western Riverina	3876	3700	3393	3126	3672	3396	3294	3008	1545	1880	15822	15145	30967
	25%	24%	22%	21%	23%	22%	21%	20%	10%	12%			
GMAHS	24%	24%	21%	20%	22%	22%	21%	20%	11%	14%			
NSW	22%	21%	22%	21%	23%	23%	21%	21%	11%	14%			

Source: Census of Population and Housing, 1996, as cited in the GAPS project proposal

Table 2 Structural elements in place prior to the project and from June 2002

Service (2000)	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 policy & procedure manual and training (0.4 + 0.4 RN also)
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 hours	No formal arrangements around palliative care	Roles defined to include attending case conferences, on Governance Committee
General Practitioners (Griffith, Coleambally, Hay, Leeton, Hillston)	Practice hrs plus some rostered on call for own practices	No formal arrangements around palliative care	Griffith GPs (approx 10) attending case conferences Some nursing substitution of on-call workload.
Emergency Department, (Griffith Base Hospital)	On call	VMO roster for admission to wards. RMOs/VMOs ED roster	GP palliative care roster, ED RN (0.4 FTE) coverage, Policy has roles delineated and procedure manual in place
Pastoral care network (Griffith and other localities)	Across via Ministers Fraternal and Multicultural Council	No formal arrangements about palliative care except through chaplain role in hospital	Attendance at case conferences and role in policies and procedures
Volunteer support network (Griffith & Hillston)	24 hrs	Patient allocation by volunteers. No paid coordinator	Roles as described in policy and procedure manual
Cancer Patients Assistance Society (Area-wide)	Ad hoc basis	Through oncology unit	Role as described in policy and procedure manual

The model of service delivery is built around the following direct-care components:

1. The adoption of common referral criteria for palliative services so that access is improved and extended for people with non-malignant conditions;
2. The adoption of weekly, one hour case conference meetings involving GPs, community nurses, and staff from the Griffith Base Hospital oncology/palliative care unit;
3. The creation of a single 1800 number to provide 24 hour/ 7days access to palliative care services.
4. Local GPs being given VMO arrangements at Griffith hospital to allow them to attend their palliative patients if they present to the emergency department or are admitted;
5. The adoption of service protocols that promote continuity of care. For example, an agreement that palliative patients admitted from the ED are transferred from the on-call specialist to their principal carer the following day;
6. The creation of a patient-held record so that each service provider is aware of the care provided by others, and so that patients can avoid unnecessary delays and investigations if seen by a clinician unfamiliar with their history;

7. The negotiation of access to specialist palliative care units, and
8. The delineation of roles for volunteer groups.

In addition to these direct care components, the model also includes various supporting components:

1. The implementation of an computer information system that enables richer patient data to be stored and analysed, and that facilitates a more consistent approach to patient assessment;
2. The introduction of a sticker in patient medical files to identify them as palliative;
3. Expanded professional education for staff;
4. Training for pastoral workers and volunteers;
5. The advertisement of the 1800 telephone number to the community.

The final component of the project is its management and governance structure. A project manager (with a background in palliative care nursing) was employed to coordinate developments, and a Board of Governance was created to oversee the functioning of the project. The Board contained representatives from GMAHS and MDGP plus representatives from pastoral care and the community. The Board of Governance has met on a monthly basis.

The project was financed from State and Commonwealth funds. The Commonwealth contribution (excluding evaluation costs) was \$288,859 for the 3-year period. This covers half of the project coordinator's salary, the leasing of a car and equipment, and other incidental and administrative costs. The State contribution of \$89,298 per annum is used to cover the other half of the coordinator's position, a fractional amount (0.2 FTE) of the Area program manager position, as goods and services (\$3,000), and the cost of the 1800-number on-call service (\$22,500). An enhancement grant under the NSW Complex and Chronic Care Program pays for additional costs in Griffith and \$10,000 is set aside to cover assistance from the Area's Public Health Unit.

Much of the initial project development did not seem to require the enhancement of recurrent funding, including integrated patient-centred records, clinical guidelines, information system development. The project required small amounts of capital to purchase computer hardware and software, and to lease a vehicle for the project manager. Services provided by GPs are covered using the Medical Benefits Schedule items, with the Enhanced Primary Care items being used to cover the case conference meeting costs. The key aspect of the model that appeared to require an increase in recurrent funding related to the identified gaps in service delivery and where activity fell significantly short of National Standards.

In summary, the model of care incorporates many of the principles outlined in the National Palliative Care strategy (see Appendix 2), as well as the service standards proposed by Palliative Care Australia, and the framework proposed by NSW Health. As such, the model of care includes components adopted by other palliative care initiatives (for example, the SW Sydney Area Health Service extended palliative care service). Yet, these similarities should not overshadow the unique aspects of the project. The rural location of Griffith poses particular problems in terms of the level of services that can feasibly be funded given the population base. Moreover, the rural context raises other issues that metropolitan services either do not have to address or can deal with in more ways, such as distance, availability and retention of staff, communication between carers, pastoral care and volunteer support, and information management.

4.2 Changes implemented over the first months of the project

The progress that the project had made by June 2002 in implementing its model of care was described in the mid-term evaluation report. These changes have largely remained in place for the duration of the project and so a brief summary of these changes is provided in this section.

The project began enrolling patients in October 2001, and made rapid progress in implementing strategies to meet the project objectives. Credit for this lies with the Board of Governance, the project manager, and the stakeholders who invested considerable time in planning prior to the project.

An overview of the changes implemented by June 2002 is given in Table 3. Changes to individual services were also included in Table 2 alongside the project's starting position. As Table 3 shows, the project was quick to adopt changes in procedures that promoted continuity of care and provided better after-hours coverage.

Table 3 Interventions implemented by June 2002

<p>Direct care activities</p> <p>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;</p> <p>Provision of a 24 hour 1800 number for advice, intake, referral and coordination of after-hours call-outs as required;</p> <p>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;</p> <p>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.</p> <p>Weekly case management review involving Oncology/Palliative Care Nurses, Community Nurses, Private Nursing Agency, GP representatives, Allied Health and liaising with Emergency Dept and Pastoral Care;</p> <p>Joint intake decisions by the case management team;</p> <p>Information booklets on palliative care for patients, family and friends.</p>
<p>Supporting activities</p> <p>MDGP-based administrator attends weekly case reviews to coordinate uptake of EPC items;</p> <p>An integrated patient-held medical record created; record shared across and written into by all services involved in the patient's care;</p> <p>Sticker added to medical records of enrolled patients to allow easy identification;</p> <p>Establishment of an information system that satisfies National Standards for Palliative Care;</p> <p>Development of a computerised information system around the PalCIS software, and Palm Pilots to allow data entry at the point of assessment/service delivery;</p> <p>Television advert aired to inform community about the project.</p>
<p>Management and Governance</p> <p>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;</p> <p>Appointment of a Project Manager jointly funded by the GMAHS & MDGP for the initial 2 year term of the project;</p> <p>Routine collection of data, monthly monitoring and progressive evaluation against nominated performance indicators.</p>

Some of these initiatives are worth discussing in more detail. First, the weekly case conferences were chaired by the project coordinator unless unavailable, in which case the on-call nurse took over this role. The review discussion was helped by the use of symptom assessment tools when service providers visited the patients. The current phase of a patient was discussed, together with

current needs and treatment options. The meetings were also an opportunity for the coordinator to update or collect missing data.

Second, the on-call nurses operating the 1800-number were rostered on a weekly basis, with a cycle of around four weeks. A longer cycle was considered to be undesirable as the nurses felt they lost contact with patients. The roster involved nurses from all participating agencies and was organised and managed by GMAHS. Any call to the number is triaged by the nurse who decides whether a patient visit is required, the GP should be notified, or the patient should attend the hospital.

Third, the computerised information system was built around the PalCIS software developed in Western Australia for palliative care services. The software is designed to support clinical activities, allowing for the collection of patient and carer details, various palliative care health status instruments, the phase of care, and characteristics of care delivered by services. The software can be loaded onto Palm Pilots so that data can be entered at the time of a (home) visit. The project purchased the software and several Palm Pilots with the aim of using it in this way. The software would allow the project to conform with various data reporting requirements, including the National Minimum Data Set for palliative care, and the NSW Health performance indicators. NSW Health had been moving towards collecting AN-SNAP data on palliative care episodes, and the PalCIS system included all data items required by the classification.

Finally, the management of the project was required to conform with NSW reporting requirements for Area Health Services, in particular, in relation to the Chronic and Complex Care program into which palliative care has been placed. On a policy level, the Chronic and Complex Care program can be interpreted as imposing specialist models of primary care activities, and favouring organisational structures that, unfortunately, may lead to further fragmentation rather than coordination. On a practical level, the program requirements led to the project adopting around 50 performance indicators, a considerable administrative burden, but one which was adopted to help the project to become mainstream.

Not surprisingly, by June 2002, some of the planned changes had either yet to be implemented, or were in their early stages of development. These included:

- Training for volunteers, procedures for greater involvement;
- Education opportunities/material for staff;
- Service limitations due to the lack of psycho-social counselling;
- Bereavement support, minimum involvement of pastoral care; and
- Lack of volunteer involvement.

4.3 Reaction to project and other issues: mid-term evaluation results

By June 2002, the evaluation team had been able to collect a variety of data on the progress of the project, covering the changes in processes, the reaction of the staff involved and the expectations of stakeholders. Data on patient reactions were not available.

The project had enrolled 52 patients, of which 27 had died. The case conferences appeared to be working well, after an initial learning phase. Communication had improved and there had been a general acceptance of arrangements for shared care. The cultural change for service providers was being managed effectively, and the project manager, with the Board of Governance, was providing the project with strong leadership.

The initiatives to improve service access and coordination were viewed very positively by clinicians and stakeholders, with views expressed in interviews being positive across a range of issues. For the nurses, there was the potential for sharing the workload more evenly, and more professional

support with community nurses linking up with the oncology unit nurses. The 1800-number and on-call roster were providing improved quality of care, and there was general acceptance of the GAPS model of care. Nonetheless, the approach of integrating palliative care services could also be seen as a fragmentation of the oncology service, which was not seen by all as desirable since the majority of palliative patients had oncological conditions.

The impact of the project on GPs had also been immediate. The role of the GP in the system before GAPS and up to June 2002 is described in Table 4, summarising data collected from interviews, observations and the GAPS information system.

Table 4 Changes to the GP role by 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	Perception of fewer ED admissions (no data in June to confirm)
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

The changes to how the GPs work were an important part of the new arrangements. The GAPS model of care is regarded as having a strong generalist base, a fundamental requirement being to support GPs, not least because of the continuing shortage of GPs and other specialist expertise in rural areas. The role of the Murrumbidgee Division had been very important, both in providing organised GP input, and by sharing administrative burdens in ways that make the project very 'GP-friendly' (such as administrative support for EPC claims).

There were no reports of unintended impacts or disagreements about cost shifting. The ongoing development of the policies and procedures, and the governance arrangements, appeared to be preventing these from occurring. The dangers associated with such movements were not lost on the project. For example, a potential outcome of Commonwealth initiatives like the Better Mental Health Outcomes program was a movement of scarce and expensively trained staff from Community Health to GP Divisions. This was raised as a threat that might well need to be managed through the auspices of the project. Of course, 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. But by including representatives from the Area, community health, hospital, private nursing and GP interests in the governance structures, the project appeared well placed to manage these structural difficulties.

Various issues were still facing the project in June 2002. Among these was how to best meet bereavement needs and patient's and carers' spiritual needs. Another unresolved issue was how to strengthen the role of volunteers, and whether a paid volunteer coordinator was required. A contributing factor to the lack of support for volunteers was a shortfall in psychosocial counselling services. The lack of psychosocial services was a recognised weakness, leaving more work for pastoral care than might be reasonable. The problem was expected to be more pressing when the project was extended into outer rural areas and has to deal with large distances to outlying villages and properties.

Various occupational health and safety issues arise from a home-based model of service delivery, issues that are exacerbated by greater distances and more difficult communication (safety after

hours, communication black spots, travelling long distances especially at night). These were being formally addressed by the project, and policies and procedures were expected to be refined. At June 2002, though, these were still being developed.

Finally, while the PalCIS information system was providing valuable data for clinical and management purposes, the analysis of the data highlighted a number of teething problems. The completeness of the data was variable. In particular, although a reduction in the use of emergency departments was a key objective, emergency department information was not being collected. Also, data about phase changes and the health-status of patients were not always entered, and it was not clear if the Phase item was being scored appropriately. This would prevent the data meeting the data collection requirements for the AN-SNAP classification. Staff reaction to the Palm Pilots was also mixed; most patient data appeared to be written only in the patient held record.

4.4 Project developments between June 2002 and March 2003

The project continued to develop after June 2002, making various changes to how palliative care was organised as well as implementing other supporting activities. A number of the more substantial changes are outlined in this section.

Restructure of nursing roles

A significant change occurred during this period in the way that domiciliary nursing for the GAPS project was organised. Formerly, day-time home visits to GAPS patients were made by a combination of community nurses and the nurses from the hospital oncology unit. Some difficulties arose in the organisation of case management between these two services, and because the oncology nurses had regular commitments to clinics during the week.

These issues were resolved by assigning the community nurses as primary case workers for domiciliary patients. The oncology nurses no longer undertook day time visits to patients and instead concentrated on their hospital based work and developing the GAPS service for outlying areas. This change reduced the number of nurses that were available to undertake home visits during the day from four to two full time and one part time nurse.

It was clear that these changes in roles caused some anxiety among the staff. Another result of this restructure was the initiation of a regular nurses meeting to work through the issues relating to the case management of patients and to resolve any conflicts. By December 2002, the Board of Governance Minutes report that the meetings had been "very useful" in dealing with potential problems.

New Coordinator of GAPS

In April 2003, the project coordinator of GAPS began his new role as the National Consultant to the Rural Palliative Care program. He formally resigned from the GAPS Board of Governance on 7th May, but will remain in an advisory capacity. The GAPS coordinator position, which was formerly funded by the Murrumbidgee Division of General Practice, is now a Greater Murray Area Health Service Position. The position was filled in April 2003.

Project expansion: Coleambally, Darlington Point and Hillston

By 2003, the GAPS project had been expanded to include the towns of Coleambally, Darlington Point and Hillston. The GAPS project formally began in Coleambally on 11th September 2002 after a series of meetings and education sessions with the staff. The Coleambally expansion was launched officially by the Federal Minister for Health, the Hon Kay Patterson, on 9th April 2003.

The Coleambally team has a GP and a community nurse, and there are currently five patients on the GAPS project. Calls by patients to the 1800 number are managed through Griffith and referred on to the Coleambally staff, but the Coleambally team has a separate multi-disciplinary case conference meeting to discuss their patients. The Coleambally GP is able to contact Griffith GPs for support and guidance.

By December 2002, there were several patients on the GAPS program in Darlington Point. Darlington Point is 25 kilometres outside of Griffith and so extends the original 15 kilometre radius of the project. Darlington Point patients come into Griffith to access GAPS services, but are able to use the 1800 number for advice. The inclusion of these patients in the GAPS project was formalised in 2003.

With the expansion of the GAPS project to Coleambally, Darlington Point palliative patients are now managed through Coleambally, with backup if required from Griffith. There are two nurses on call in Darlington Point and one GP.

Preparations during the period June 2002-May 2003 were also being made for the expansion of the project to Hillston (120 kms out of Griffith). There are currently two on-call nurses in Hillston and one GP. There is a need for a third nurse to join the on-call roster in Hillston to make the expected workload manageable. At the time of this report, no patients had been enrolled.

Residential Aged Care staff training

The GAPS Coordinator attended a meeting with representatives of the Griffith residential aged care centres, who were keen to be linked with the GAPS program. In conjunction with this proposed expansion, the Coordinator planned to develop or modify educational material to be used in training of nursing home staff. This initiative is still at the planning stage.

Development of an educational CD-ROM and promotional video

GAPS developed a CD-ROM, with various members of the staff outlining different aspects of the service. It is intended that the CD-ROM becomes part of a training package as the model of care is transferred to other areas. In addition, the GAPS team developed a promotional video. Its launch coincided with the opening of the Coleambally service by the Commonwealth Health Minister. The video briefly outlined the purpose and aims of the GAPS project and gave many of the staff the opportunity to talk about their perceptions of GAPS.

Organisation of State Palliative Care Conference

Palliative Care NSW provided GAPS with a \$10,000 planning grant to organise the Annual State Conference in Griffith in November 2003. A subcommittee has been formed to undertake the tasks necessary to organise the conference and, by May 2003, the list of keynote speakers (including an international speaker) had been finalised.

4.5 Evaluation activities since the mid-term evaluation report

The evaluation team continued to maintain contact with the project from June 2002, visiting Griffith several times to interview staff, and participating in Board of Governance meetings via a teleconference link. The primary aims of this phase of the evaluation were to assess the impact of the project on patients, and examine the broader issues of project sustainability and generalisability.

In addition to the overall approach of collecting quantitative and qualitative data, this phase of the evaluation included a three-week ethnographic investigation of the functioning of the project, and its impact of patients and their carers. For this, a researcher accompanied staff as they undertook their work, and (if they consented) spoke to patients and carers about their experience of the

condition and care. This provided an in-depth view of the issues affecting patients and carers, and how they were being managed (see Appendix 3 for more details).

The final phase of the evaluation did not undertake various activities envisaged in the Mid-term report. First, the audit of records on pre-GAPS patients provide insufficient patients for a control group that could be used to compare service utilisation by matching enrolled patients with a pre-GAPS equivalent. Second, the limitations of the NSW Health DOHRS information system meant that it was not possible to collect data on palliative care delivered by community services from another comparable location. Finally, it provided not to be possible to locate a comparable rural location which had data on EPC usage. Despite this, we believe that the ethnographic approach allowed us to accurately document the impact of the project, and that our conclusions about generalisability are valid.

5. Patient well-being and service activity: quantitative analysis

5.1 Availability of quantitative data

Quantitative data on project activity were collected from two sources. The main source was the PalCIS software that formed the basis of the information system developed to support clinical and management/governance processes. It contained various patient and service delivery information collected when a patient was enrolled into the project, and whenever they or their carers received services. The second source of data was the log of patient calls to the 1800-number. These were recorded on paper-based forms, which had to be summarised and entered into a computer for analysis.

The analysis of data in this chapter is focused primarily on the PalCIS data. The results of this analysis are described in Sections 5.2 to 5.5. Statistics on the 1800-number are described in Section 5.6.

Information about the progression of a patient's condition is primarily organised around the concept of episodes (phases) of care. Five-categories of phase are defined - Stable, Unstable, Deteriorating, Terminal, and Bereavement – that correspond to a broad rating of a person's health state and prognosis. Definitions of each of the palliative care phases are provided in Appendix 4. Individual phases are associated with different levels of demand for services, and provide an accepted framework within which to summarise data. Nonetheless, there are generally important differences among patients within these phases, and the number of patient assessments and occasions of services will vary across distinct phases.

5.2 Characteristics of the data collected within PalCIS

The PalCIS software allows data on various types of services to be collected. Data fields related to direct occasions of service are included for inpatient, outpatient, and domiciliary nursing services, while others are related to indirect activities such as case conferences. Data on other services (like emergency department visits) can be collected with user-defined fields. The software also supports a consistent approach to patient assessment by including a variety of standard health status instruments, namely:

- The Karnovsky index, which rates the ability of a patient to perform their normal daily activities;
- A system assessment scale (SAS) 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 (pain, bowel problems and nausea);
- The RUG-ADL functional assessment score; and
- The AAHPC (now PCA) Problem Severity Index.

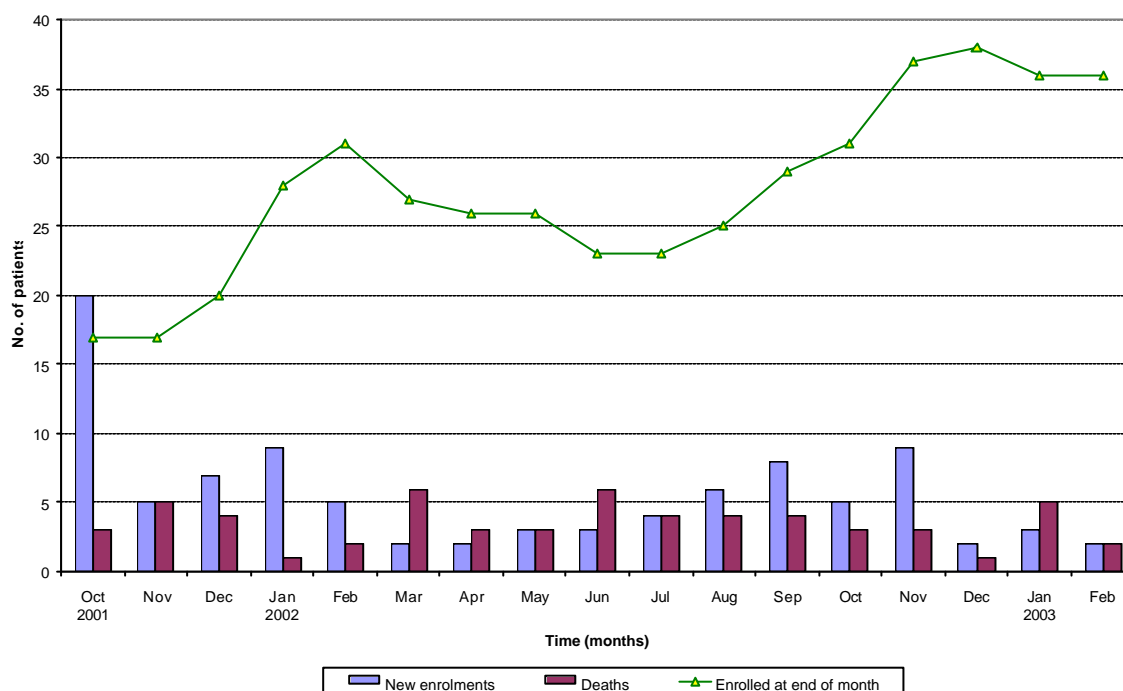
The inclusion of the RUG-ADL and Problem Severity Index, in conjunction with the Phase framework, means that the PalCIS software supports the AN-SNAP casemix classification for palliative care. The AN-SNAP classification has the potential to support management activities by allowing clinical level data to be converted into information about expected resource use. In addition, the AN-SNAP classification has been adopted for reporting purposes within NSW.

The project provided data that covered the period from October 2001 until the end of February 2003. There were 95 patients enrolled within this period. Twenty of these patients were enrolled in the initial month of October. After this, the number of referrals fluctuated between 2 and 9

patients per month, the average being 4.7 per month. The number of deaths per month was on average 3.5, ranging from 1 to 6. By March 2003, a total of 59 patients had died.

The number of patients enrolled in the project, after the initial build up over its first four months, ranged between 23 and 38. The number of patients steadily increased from June 2002 from the around 25 to the maximum number of 38 (see Figure 2).

Figure 2 Number of patients registered with the GAPS program (Oct 2001 - Feb 2003)



The majority of patients (64 of 95) were categorised in the stable phase on referral to the project. The next most common phase on referral was unstable (n=15), followed by deteriorating (n=12) although almost all patients categorised as deteriorating on referral occurred during the initial start up period. Two patients were referred on the day of death for family bereavement management.

There was a wide range of primary conditions among the referred patients, making analysis by condition of little value. There were 12 patients with non-malignant diseases among the 90 patients with a clear primary diagnosis. These included patients with multiple sclerosis and motor neurone disease. Among the most common malignant conditions were cancer of the pancreas, colon, breast, prostate, and lymphoma and multiple myeloma.

PaICIS contained a series of assessment data for patients. On most occasions, the Karnofsky, SAS, RUG-ADL and Severity Index were administered on the same visit (see Table 5). There were differences in the degree to which the data were complete. In relation to the SAS items, each record contained at least the nausea, bowel problems and pain scores, enabling the summary PBN score to be computed in all cases. The number of records missing scores for insomnia, appetite, breathing and fatigue ranged between 17 and 26. The items for Quality of Life, Satisfaction and Wound Index were collected only rarely. In relation to the Severity Index, 46 of the 444 records were missing; none of the RUG-ADL data were absent.

The number of visits per patient when at least one scale was collected is summarised in Table 6. There was considerable variation among patients in the number of times assessment data were collected. Some patients had 12 or more such visits, yet 28 of the 95 patients did not have any

assessment information. The number of assessments that a patient had was not strongly related to the length of time the patient had been enrolled.

Table 5 *Combination of health status scales completed at visit*

Scales completed	Frequency
SAS, Karnofsky and AN-SNAP scales	372
SAS and Karnofsky	70
SAS and AN-SNAP scales	17
Karnofsky and AN-SNAP scales	41
SAS only	53
Karnofsky only	15
AN-SNAP (RUG-ADL and Severity Index) only	14
Visits at which at least one scale was completed	582

Table 6 *The number of visits at which assessment data were recorded per patient*

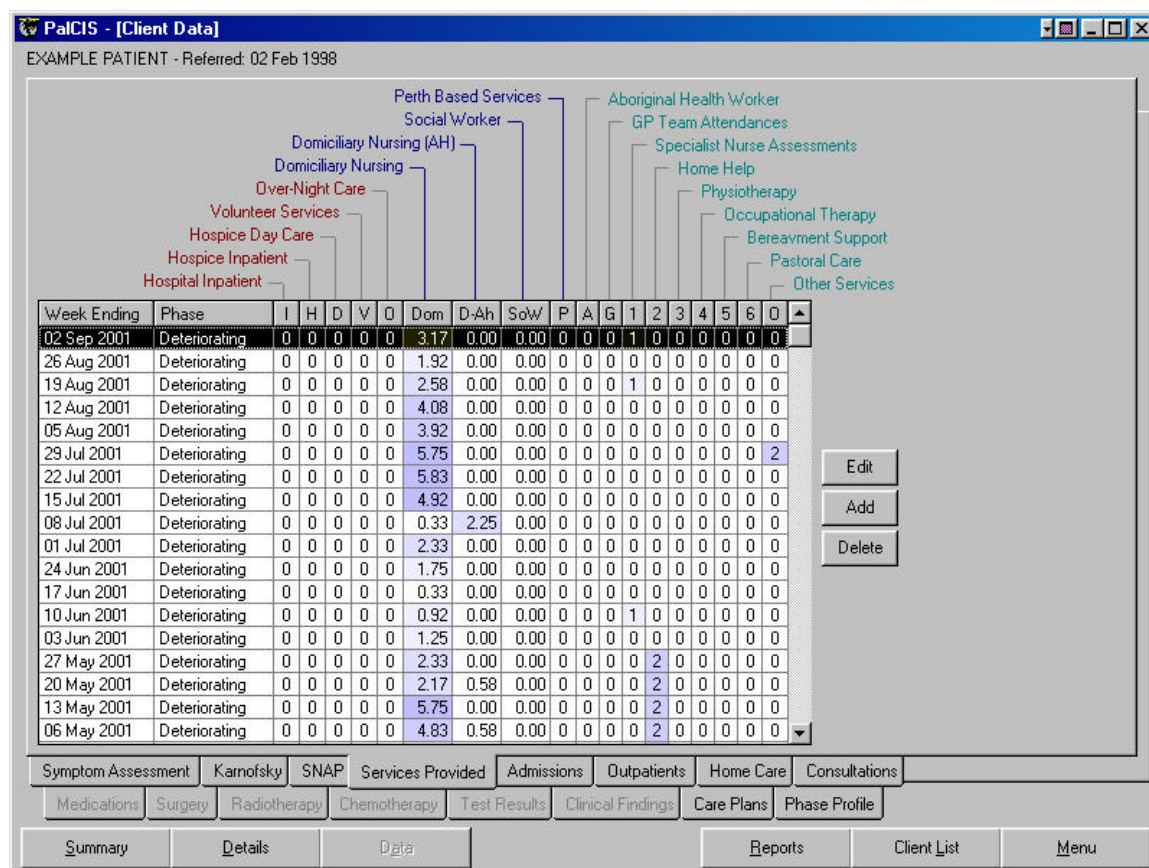
Number of visits	Patients with at least one type of data	Patients with SAS data	Patients with Karnofsky data	Patients with AN-SNAP data
0	28	28	29	34
1	14	17	16	19
2	4	3	6	5
3	7	8	5	4
4	6	6	5	3
5	2	0	2	2
6	2	3	3	1
7	4	3	3	2
8	0	2	1	2
9	1	3	2	2
10	4	2	4	3
11	2	2	2	3
12	21	18	17	15

As noted above, the Phases, RUG-ADL and Severity Index data are required to allocate episodes of care to palliative care AN-SNAP classes. Unfortunately, there were several technical issues with the GAPS data that prevented this. First, on the 453 occasions when the phase of someone changed, RUG-ADL and Severity Index data were not always available. Sometimes the data were incomplete, but it was also because a phase could be changed at a case conference meeting and this not always followed by an assessment. In addition, there were several instances when the interval between assessments was greater than the 90 days, which is not permitted under the AN-SNAP classification rules. Consequently, due to this issues and the small number of patients in the sample, it was decided not to try allocating patients to AN-SNAP classes.

Information on the services delivered to patients could be entered in PalCIS in two different formats. The first allows data on individual occasions of service to be entered. The second allows the overall amount of services delivered on a weekly basis. Figure 3 shows the weekly summary of services screen (dummy data), and illustrates the range of services that might be collected. PalCIS offers a range of standard service types and up to six user-defined categories (headings 1 to 6 across the top of the table). The types of individual episodes that the project could collect information on in this version of PalCIS are shown in the (bold) tab labels at the bottom of the

screen namely home care (domiciliary nursing); hospital admissions; outpatient visits; and case conferences/ consultations.

Figure 3 Date entry screen for the weekly summary of services received (dummy data)



The project captured service use data using both formats. Data on individual episodes were entered on inpatient episodes and home care (domiciliary nursing) visits. The latter were collected by nurses entering information during a home visit into a Palm Pilot. The data were later downloaded into the main PaICIS database. The weekly summarises were predominantly used to collect GP case conference information. Of the 1,566 records of weekly activity, 1505 contained information about whether or not a patient was discussed during the weekly case conference meeting. The next most frequent entry was for hours of domiciliary nursing delivered (291 entries).

5.3 Patterns of condition progression (phase movements)

The pattern of phase movements over time among individual patients was calculated by combining the information from the (weekly) service utilisation data and the assessment data. This differs from the approach used in the Mid-term evaluation report which was based only on the phase information in the assessment data. Consequently, the two sets of results are not directly comparable, with the Mid-term figures showing much fewer changes in phase.

From the time of enrolment until the end of the data collection period (1 March 2003), the 95 patients had 453 phases of palliative care (see Table 7). The majority of these were spent within the stable phase, both in terms of number and duration. In contrast, the average time spent in the deteriorating and unstable phases was brief, being just under two weeks on average.

Table 7 Summary of phases among the enrolled patients

Phase	Number of phases	Total days spent in phase	Incomplete phases	Average duration of phase (days)*
1 – Stable	175	9708	32	68
2 – Unstable	126	1492	3	12
3 – Deteriorating	77	832	1	11
4 – Terminal	16	145	0	9
5 – Bereaved	59			

The sequences of phases among the patients showed considerable variation (see Table 8). Where complete information was available, a few of the patterns appeared more frequently than others, but the most obvious characteristic was the movement of patients from stable to unstable or deteriorating and back, up until death. A few patients cycled back and forth in this way through 10 or more phases (a sequence was 19 phases was the longest recorded). This pattern could also be seen among patients who were still alive, although to a lesser extent. Among these patients, the majority had remained in the stable phase.

For the complete phase sequences, there was a weak association between the number of phases in a sequence and the length of time a patient was enrolled in the project (Pearson's $r = 0.55$). A stronger association was not expected because the sequence is likely to depend on the nature of a person's primary illness as well as their general health status.

The duration that individual patients were enrolled varied widely. The average time enrolled was 147 days, but the duration ranged from 2 to 509 days. This is higher than the estimated duration for pre-GAPS patients (105 days), but it is also an underestimate for the cohort as many patients were still alive at the end of the data collection period. Among the 59 patients who had died, the minimum and maximum duration was 2 and 391 days (excluding the two patients enrolled in the project so their families received bereavement support). The average time enrolled was 93 days. Among the 36 active patients, the average duration was 234 days. Of these, 16 had been enrolled in the project for more than six months.

Table 8 Common sequences among the 95 patients

Complete phase sequences	Frequency	Incomplete phase sequences	Frequency
5 only	2	1-	18
1-5	6	2-	1
2-5	2	1-2-1-	3
3-5	3	1-2-3-2-	2
4-5	1	1-2-1-2-1-	2
1-2-5	2	1-2-1-2-1-2-1	2
1-3-5	2	Other sequences	8
2-1-5	3		
3-4-5	3		
4 phase sequence	5		
5 phase sequence	5		
6 or more phase sequences	19		
Total	59	Total	36

5.4 Health status scores and preferred/actual place of death

There was considerable variation in the well-being of clients when referred to the project. This can be seen most easily using the Karnofsky index. This brief functional assessment uses an 11-point scale from 100 (normal, no complaints) to 0 (dead); intermediate points include 70 (cares for self, but less than normal), 50 (requires considerable assistance) and 30 (almost completely bed-fast). Of the 65 patients who had a Karnofsky rating, the scores at the first assessment covered the complete range (from 100 to 10). Nine patients were almost bed-bound, or worse, while another eight were bed-bound more than 50% of the time. Twenty-two patients were rated as requiring assistance (scores of 50 or 60), while 26 patients were initially rated as able to care for themselves. Among the 42 patients who died during the project and had at least two scores, 29 patients had a final rating as mostly bed-bound (40) or worse.

The preferred place of death had been recorded for 48 patients. Most patients preferred this to be at home (n=37), while nine preferred the hospital. Of these 48 patients, 28 had already died. Twelve of the twenty-one that had wanted to die at home did so. The other nine patients died either in hospital (5) or at a nursing home (4). Three of the six patients who wanted to die in hospital did so (only one died at home).

In the remaining part of this section, the focus of the analysis is on how the health status scores varied by phase as the phase categories are likely to be associated with different levels of health status. However, interpreting the distribution of scores within each phase is not straightforward. First, there were no data for some phases of care. If the data were not recorded for some systematic reason, such as the patient being too unwell to give an answer, then these missing data will cause the distributions to be biased. 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 9. For the PBN scores, the distribution of scores does not differ much between phases. Within the three phases with over 100 observations, the data extended from no symptoms to the very high symptom ratings. However, patients in a stable phase generally had low scores (95% have values of 10 or less) and there was a significantly greater proportion of higher scores among patients in the other phases. In relation to the pain component, pain was rated as greater than 5 on 48 occasions, with 17 of these relating to patients in the stable phase. In most cases, the period over which the pain score was above 5 did not last long.

As noted above, the Karnofsky index uses an 11-point scale from 100 (normal, no complaints) to 0 (dead) to measure function. As such, it is not surprising that there is a relatively strong relationship between phase and the Karnofsky index. (The rating of "dead" for someone in the terminal phase appears to be a data error.)

The RUG-ADL scale is a more detailed measure of functional dependency than the Karnofsky index, measuring the assistance someone needs with bed mobility, toileting, transfer, and eating. In the Mid-term report, there was not a strong relationship between phases and the distribution of scores, which was unexpected given that the AN-SNAP classification study had shown a clear relationship between phase and the RUG-ADL. The larger sample of data now available shows a stronger relationship between the two variables, and distributions of scores that are now consistent with the AN-SNAP study (see Figure 4).

Table 9 *Distribution of assessment scores by phase for the PBN, Karnofsky, RUG-ADL and Severity Index instruments*

PBN scores (score increases with worse health)

Phase	#Patients with this phase	#Patients with a score	Number of scores	Minimum	25 th percentile	Median	75 th percentile	Maximum
1	75	50	266	0	0	2	5	25
2	45	32	107	0	1.5	4	12	23
3	30	28	105	0	1	3	9	25
4	12	12	27	0	0	2	8.5	16
5	59	7	7					

Karnofsky scores (score decreases with worse health)

Phase	#Patients with this phase	#Patients with a score	Number of scores	Minimum	25 th percentile	Median	75 th percentile	Maximum
1	75	49	262	100	80	70	60	30
2	45	30	99	100	60	50	40	20
3	30	28	101	90	50	40	30	10
4	12	11	27	60	40	20	20	0
5	59	9	9					

RUG-ADL scores (score increases with worse health)

Phase	#Patients with this phase	#Patients with a score	Number of scores	Minimum	25 th percentile	Median	75 th percentile	Maximum
1	75	43	224	4	4	4	6	18
2	45	27	90	4	4	6	10	15
3	30	28	100	4	9.75	13	15	18
4	12	10	24	6	10	14.5	16	18
5	59	6	6					

Problem severity scores (score increases with worse health)

Phase	#Patients with this phase	#Patients with a score	Number of scores	Minimum	25 th percentile	Median	75 th percentile	Maximum
1	75	41	197	0	4	4	6	12
2	45	25	84	0	4	5.5	7.25	12
3	30	27	92	0	5	7	9	12
4	12	8	19	0	0	5	10	12
5	59	6	6					

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 10). However, in some respects, they are complementary. The middle Karnofsky items are not particularly precise, being defined as:

- 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 between 30 and 60. 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. It seems desirable for the project to continue collecting both because there appears to be considerable local support amongst clinicians for the Karnofsky scale, while the RUG-ADL is required for the AN-SNAP classification.

Figure 4 *Quartiles of the distribution of RUG-ADL and Problem Severity scores by phase as recorded in the Griffith and AN-SNAP studies*

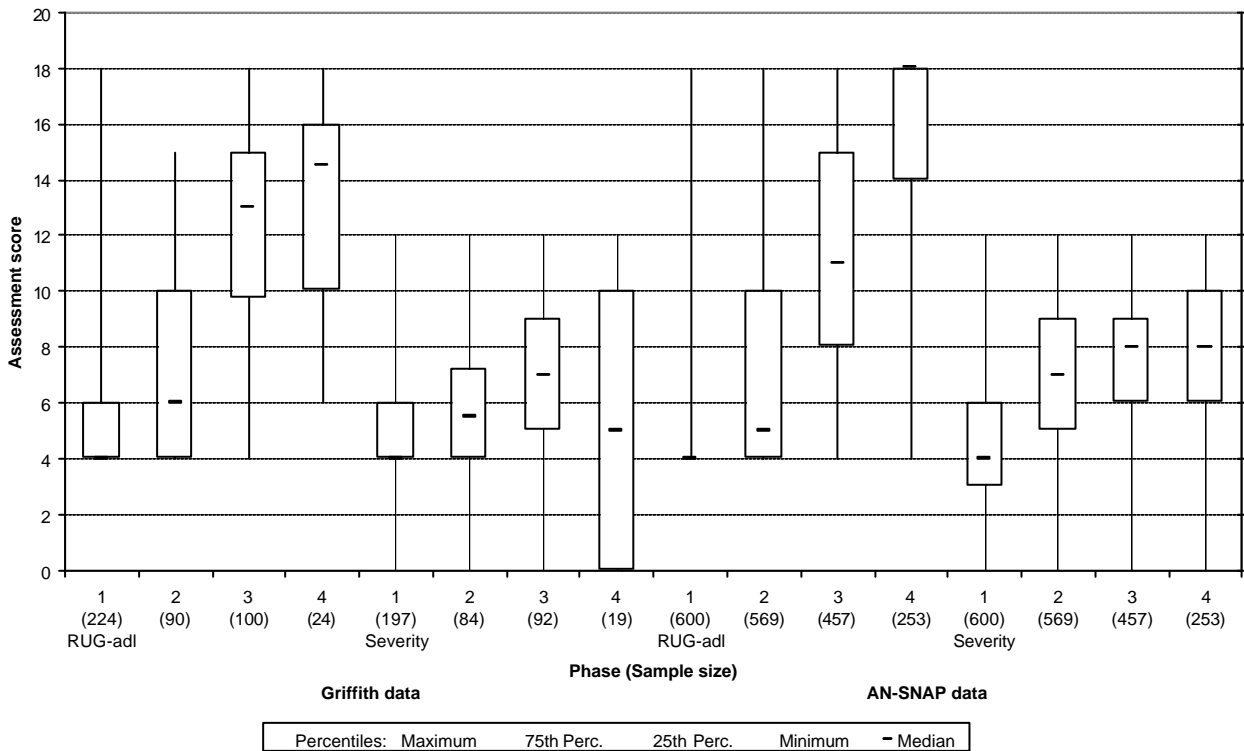


Table 10 Distribution of Karnofsky and RUG-ADL scores

RUG-ADL scores	Karnofsky scores										Total
	10	20	30	40	50	60	70	80	90	100	
4			2	2	8	31	22	43	32	1	141
5				3	4	13	7	11			38
6			2	6	10	15	3	2			38
7				2	2	1					5
8			3	3	3	7		2	1		19
9			4	3	1	1					9
10			5	5	12	8					30
11		2	4	3	5	1					15
12		3	8	6	1	1					19
13			7	1	12	2					22
14		2		2	9						13
15	5	16	15	4	1	2					43
16	2	1	1		2						6
17		2			1						3
18	4	6		1	1						12
Total	11	32	51	41	72	82	32	58	33	1	413

In the mid-term report, the relationship between phase and the scores of the AAHPC Problem Severity Index was also reported to be weak, although the distributions of scores were more similar to those reported by the AN-SNAP study. The larger sample of data for this analysis produced similar distributions of scores for phases 1, 2 and 3 (see Figure 4) and a distribution for patients in phase 4 that more closely approximates the AN-SNAP data. There is a general shift in the severity scores towards higher values across the phases, as might be expected, but overall there is still considerable overlap between the distributions.

5.5 Service utilisation

Comparing the recorded activity in the detailed records and the weekly summaries showed that the detailed records were under-recording activity. Consequently, the analysis of service utilisation data was limited to the weekly totals. The analysis concentrated on service use within a phase, but also examined changes in use over time. 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 compare service patterns with levels recorded in the AN-SNAP study. The association between assessment scores and service data was also not examined for this reason.

The number of units of service for each of the fields containing data are summarised in Table 11. 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.

Service use per phase can be seen to be highest for the stable phase (except for 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 the 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 confirm that every patient is discussed at least briefly at the weekly case conferences. The figures on inpatient days across the phases are too low to show any significant variation by phase.

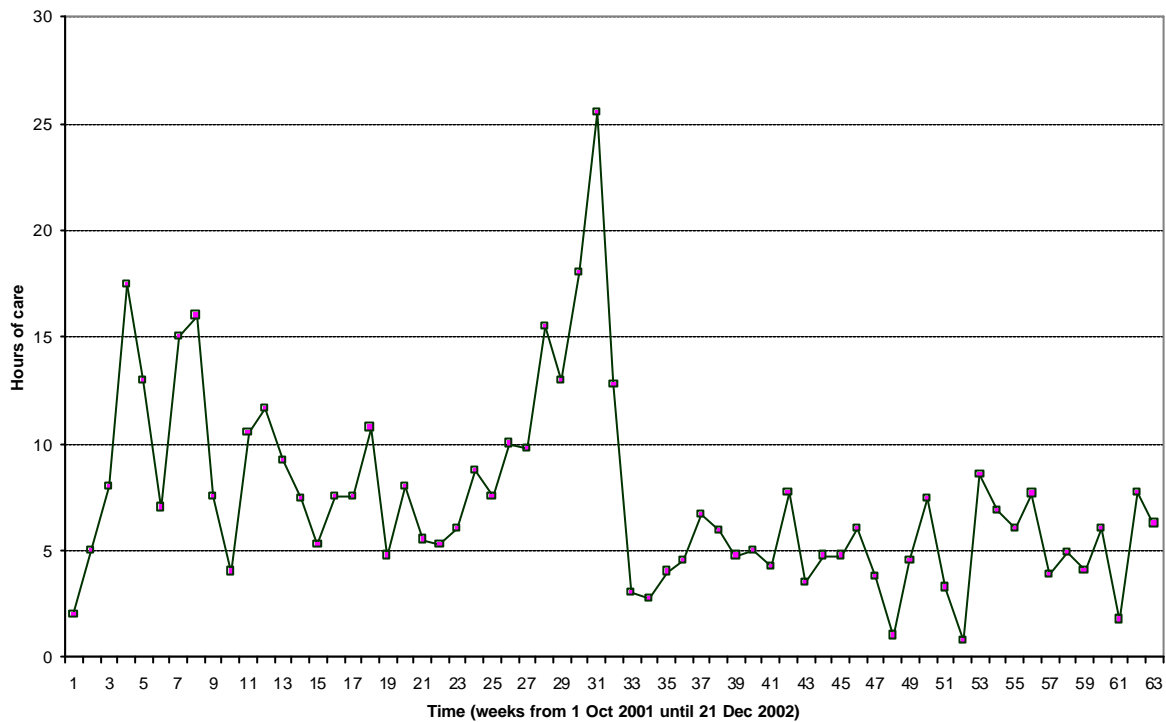
Table 11 Summary of weekly service utilisation data

Services	Unit	Phase				
		Stable	Unstable	Deter.	Terminal	Bereave
Hospital Inpatient	Days	470	95	28	1	14
Dom. Nursing	Mins	15990	4575	4995	1275	1185
Dom Nursing (After-hours)	Mins	130	300	0	140	0
GP team attendance	Occ	1062	128	80	19	49
Other services	Occ	129	112	38	34	81
Number of phases		158	110	68	16	52
Number of complete phases		103	78	61	16	52
Number of days		7567	959	574	133	525
Services per complete phase						
Hospital Inpatient		4.56	1.22	0.46	0.06	0.27
Dom. Nursing		155.24	58.65	81.89	79.69	22.79
Dom Nursing (After-hours)		1.26	3.85	0	8.75	0
GP team attendance		10.31	1.64	1.31	1.19	0.94
Other services		1.25	1.44	0.62	2.13	1.56
Services per week						
Hospital Inpatient		0.43	0.69	0.34	0.05	0.19
Dom. Nursing		14.79	33.39	90.91	67.11	15.80
Dom Nursing (After-hours)		0.12	2.19	0.00	7.37	0.00
GP team attendance		0.98	0.93	0.98	1.00	0.65
Other services		0.12	0.82	0.46	1.79	1.08

Although the observed pattern is consistent with expectations, these absolute figures should be treated with caution in terms of indicating expected levels of service use (with the exception of the case conference data). This is particularly so for the domiciliary nursing data. Firstly, there was a marked change in the number of hours recorded from the beginning of June 2002 (see Figure 5; no data were available past 21 Dec 2001). This seems to coincide with the time one of the nurses was away and the later ending of home visits by nurses in the hospital oncology unit in addition to those by nurses in the Griffith community nursing service. Secondly, there are various reasons to suspect that not all services received have been entered into PalCIS as around 50 patients had no nursing data recorded against them. If these patients are excluded from the number of patient-weeks in which services were delivered, then the estimates by phase increase considerably. Table 12 gives the estimates of the average number of nursing minutes delivered per week for before and after the change in work pattern.

Table 12 Average minutes of home nursing care per patient per week before and after the change in work practice

Phase	Pre June 2002	Post June 2002
Stable	50	32
Unstable	108	50
Deteriorating	132	59
Terminal	255	(no values)
Bereavement	40	24

Figure 5 Domiciliary nursing activity over time

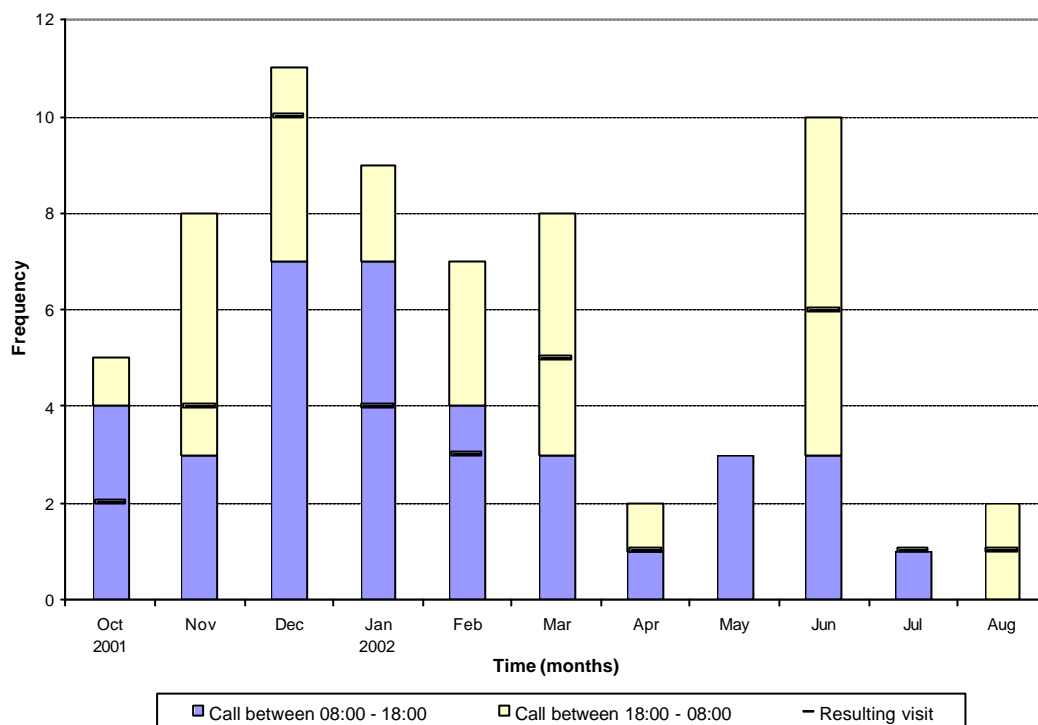
5.6 Use of the 1800 number

Data on the calls made to the 1800 number were available from 1 October 2001 to August 2002. As well as the date and time of a call, data were also recorded on the nature of the person's call (advice, reassurance, etc), and whether or not the call resulted in a home visit.

There were a total of 66 calls to the 1800 number. On 30 occasions, the call resulted in the on-call nurse visiting the patient, but on 23 occasions the call simply resulted in advice. A GP visit resulted on eight occasions, four of which were associated with confirming death. This appears to represent a reduction in the after-hours palliative work for GPs. Two calls were from members of the public who had seen the number advertised on television.

There was no obvious relationship between the time of day and when a call was made, except for the period between 08:00 and 11:00. The number of calls in this 3-hour period were slightly more than at other times (9, 3, and 7 calls respectively, compared to between 0 and 4 calls otherwise). The number of calls in each month, and whether these generated a nurse or GP visit, is shown in Figure 6.

Figure 6 Number of calls to the 1800 number from October 2001 to August 2002



5.7 Discussion

The PalCIS software provided the project with an effective means of collecting quantitative data, and the data collected represent a substantial improvement in comparison with data available pre-GAPS. A range of information is available on each patient, namely, basic demographic and clinical history, longitudinal patient health status data, and service utilisation figures. The software designers have put much effort into ensuring the software is clinical useful and it seems well-designed for that task. But implementing a new information system always takes time and effort, and a successful implementation is dependent upon a number of contextual factors. The problems with the data set noted above, therefore, need to be put into the overall context of the improvements achieved by the project.

The data extracted for the evaluation provided various insights about the project. First, the pattern of referrals and deaths gives some idea of the demand for palliative care. The average death rate of 4 per month, combined with the pre-GAPS average duration of about 100 days, suggests that initial estimates of about 10 palliative patients at any one time were broadly correct (see Section 6.1). The scope of palliative care adopted by GAPS is clearly broader than this, with at least 20 patients being enrolled at any one time. This also reflects an increase in the average time that a patient is active within GAPS, and is likely to reflect patients being referred sooner than they were previously.

Second, the health status scales clearly provide a useful picture of a person’s wellbeing. Moreover, the combination of scales collected here are mostly complementary. They appear to be have been easily adopted by the clinical staff, and have aided discussion about patients. The observed sequences of phases suggest that this variable may not have been so easily applied.

Finally, the service utilisation data provided insight into the demands placed on nursing services over the project. Although incomplete, the data clearly show the variation in demand placed on services by phase, being noticeably higher in the terminal phase. The incompleteness of the data, and the potential incorrect allocation of patients to phases, means that the figures should be

treated with caution. But it suggests that, for future projects, and community services generally, the phase framework is likely to assist in planning workforce levels and balancing workloads.

Concerns about data completeness and the use of the phase classification were raised in the Mid-term report. That these problems still exist is not unexpected. The implementation of an information system requires cultural and organisational change as well as technical innovation. Consequently, the limited use of the palm-pilot technology means that, on a practical level, it remains an unproven innovation, although the technology seems to function well. But not having data entry at the source of care poses a number of difficulties and, as here, is likely to result in incomplete data collection if this process relies on manual data entry. How this might be improved in other situations is unclear. Data entry may be eased if pre-formatted data sheets were able to be scanned, but this would need to be tested.

Various problems highlighted in the Mid-term report related to the version of PalCIS being used. The developer of the software contacted the CHSD with proposals to remove some of these problems. For example, one change would ensure that the RUG-ADL and Severity Index are collected whenever there is a phase change. The proposals appeared to be effective and user-friendly. Whether these changes were implemented within the time frame of the project is not known, but the project continued to use the same version of PalCIS.

6. Patient and staff reactions to the GAPS project

This chapter contains the reactions of patients, carers and the staff involved in the GAPS project, and summarises the qualitative data collected by the evaluation team. The views of patients and carers involved in the GAPS program were collected during a three week period in Griffith. The extended period of time provided for this research allowed the researcher to observe the day to day activities of the GAPS program and to develop relationships with the clients of the service, through regular contact. The views of staff were also recorded during this visit, but these were also collected during several shorter visits and other times of communication (ie, by telephone, email and so on). These data were supplemented by a postal survey of the 10 GPs involved in the Griffith part of the project. Each one was sent a brief questionnaire consisting mostly of closed questions on various aspects of the project (see Appendix 5). All GPs returned the survey.

A total of 14 patients or carers were involved in discussions about the service. Often, it was the carer who provided most of the information, but sometimes the patients spoke about their experiences. It was also possible to talk to three people who had cared for a relative with a terminal illness prior to the establishment of the GAPS program. One individual, with a long-term illness, was able to comment on his own experiences before and after the establishment of GAPS.

Participant observation was the primary research methodology employed in this period of the research. The researcher attempted to immerse herself in the daily activities of the GAPS service and observe how it worked for both the patients and the staff. She accompanied the community nurses on their visits to clients living in the community, attended the oncology clinics where GAPS patients received chemotherapy or attended the clinics of visiting specialists. She also visited GAPS patients who were in the Griffith Base Hospital. She also attended less routine events such as a "look good feel better" event for cancer patients, and visits to outlying areas where the service is being extended. Attending the weekly multi-disciplinary meetings, where each patient was discussed by the GPs, nurses and pastoral care staff, was a useful way of keeping in touch with the project as a whole.

6.1 Demand for, and scope of, a program that is not just for cancer patients

At the beginning of the GAPS project, it was unclear to GPs and nursing staff how many palliative patients there were in the community. Most people interviewed at the outset of GAPS considered that there were less than ten people who were in need of palliative care at the time. In addition, GPs and nursing staff were not sure who would qualify for the program. For example, there was uncertainty about when in the trajectory of a person's disease they would qualify for palliative care. There was also uncertainty about whether or not the program was intended for patients with terminal diseases other than cancer.

The definition that the GAPS coordinator used to define a palliative patient was:

"You are a palliative patient once you are diagnosed with a life threatening or life limiting disease. You can be a GAPS patient the minute you get a terminal prognosis."

He saw the GAPS program as catering to patients with a range of different needs, from being a safety net for essentially stable patients to providing 24 hour care for those in the terminal phase:

"It is not a linear progression from diagnosis to death, rather it is a series of peaks and troughs. When there is a peak, palliative care can get in and sort out the symptom control and stabilise people until they reach another peak. This requires long term planning."

This approach is in keeping with the National Palliative Care Strategy, which states:

The need for palliative care depends not on any specific diagnosis, but on the person's needs; in particular, it depends on the complexity and severity of a person's distress or potential for distress [National Palliative Care Strategy, 2000: 5]

The coordinator, however, still regards palliative care as being too focussed on cancer patients, and that there is a need for people in palliative care work to overcome the cancer focus of palliative care and palliative care research.

Most of the GPs reported referring between 4 and 10 patients over the course of the project. Two referred 20 patients, while one did not refer any. All but two patients were accepted into the project. The GPs thought the referral guidelines had been clear, and most thought that it had extended the service that had previously been provided by the oncology unit. All but one GP thought that GAPS should not be restricted to patients with cancer, but there was not a clear picture about whether GAPS could have done more to include non-cancer patients.

By March 2003, 95 patients had been referred to the GAPS program in the 17 months since the first were enrolled. There had been between 20 and 35 patients enrolled with the project at any one time, which was significantly more people than the initial estimates predicted. This may reflect people being referred to GAPS service earlier than they would have been before the program.

Most people on the GAPS program were cancer patients, who could be expected to survive less than a year; some of these patients were bed bound and unable to care for themselves. There were several patients with a terminal disease, who were expected to survive for a much longer time, such as patients with multiple sclerosis. These patients experience GAPS as a safety net, moving from being active clients in episodes where they experience a change in severity of their symptoms, to being inactive. As one client commented:

“When Dr X said I should join the project, I was worried at first. I said “I’m not that bad.” But it’s a good program, it’s always in the background for me if I need it.”

The GAPS program has extended a coordinated model of care to patients that formerly would have been excluded from the palliative care activities of the oncology unit. Patients with non-cancer terminal conditions previously would have been primarily managed by their GPs.

6.2 Patient views on being helped to stay in their preferred environment

The aim of keeping people in their preferred environment (typically at home) is greatly appreciated by patients and carers. A representative view of this was expressed as follows:

“He didn’t want to go to the nursing home, he wants to die at home, this is his house, it’s all worked out for the best.”

This patient was in the last stage of his disease. He was unable to turn himself in bed, and had to be lifted to the shower. He had a high hospital bed from which he could see through a large window out on the street; his dog lay beneath his bed and he was still able to smoke. He remained socially integrated, his principal carer was a friend, and other friends and neighbours were able to visit. He also had visits from a volunteer.

The provision of equipment and daily visits from the community nurses, enabled his carer to ensure that his wishes to be respected, and it should be possible for this patient to die at home.

In other cases, the individual’s wish to remain, and die, at home appeared to be causing their carers and their families a greater degree of stress. Although these carers emphasised the need to cope with their situation, and that their relative should not be admitted to a hospital or nursing home, it was clear that they were not coping well and were exhausted. In such cases, the community nurses and the GPs worked with the carers to overcome this stress. For example, for

one patient, the clinicians spent considerable time working out the most effective way to deal with pain whilst still retaining the carers' wishes to have the individual lucid and aware of his family. The topic was discussed in detail at a series of case conferences.

Nonetheless, the burden that patients put on their loved ones could cause anxiety for patients. One individual expressed a wish to die as quickly as possible because she thought that her illness was too heavy a burden on her family.

6.3 The organisation of nursing care: helping patients stay in their preferred environment

The changes in June 2002 resulted in home nursing care being delivered by two full time and one part time community nurses. Palliative care visits are only a portion of their workload, which also includes the routine care of people with disabilities, and providing post-operative care. The nurses comment that their workload often limits the time they can spend with palliative care patients. These time limitations are a drawback in a service that aims to provide holistic care for patients and their families. As one nurse said:

"People just want you to sit down and have a cup of coffee with them and a chat, but I have to limit myself to one cup of coffee, with one patient a day, or else I get too far behind."

There was also comment that GAPS patients may overshadow the needs of other community nursing patients:

"The problem is that GAPS takes up a lot of time. Sometimes GAPS patients take priority over aged, frail and people who need routine dressings. We have to be careful not to discriminate because of the particular needs of patients."

The community nurses indicated that the GAPS program had increased their workload:

"It's a good program, but you have to take time with palliative patients, they are time intensive. We have to see 13-14 patients a day (GAPS and community nursing patients) this stretches the quality of the service that we can provide."

Prior to GAPS the two oncology nurses made house-calls to palliative patients and this role continued as GAPS was established. In mid 2002, however GAPS management made the decision that the community health nurses would be the only nurses to make house calls during the day. This decision has had an adverse effect on the morale of the oncology nurses:

"We feel excluded from the program, the only time we have anything to do with the GAPS patients is when we are on call. Our role is being eroded."

Another community nurse commented that there were often unrealistic expectations on the part of patients, GPs and hospital staff, of what community nurses could achieve.

"Working in people's houses is difficult, they are not designed for the type of care that is needed. There are difficulties lifting patients, moving around rooms and difficulties of fitting equipment into rooms. In reality it is not possible to look after someone at home unless they have a really good carer."

The difficulty in balancing the need to allow patients to stay in their preferred environment, with managing the demand on themselves and carers was also an issue. Nursing staff recognised that it was unrealistic to expect all patients to be cared for and die at home. They talked about the high stress and demand placed on care givers and the imperative to say yes to home-based care:

"Some people are not OK about dying at home, when the crunch comes they can't do it. In the last 24-48 hours things fall apart. There is a lot of pressure on carers, especially on women by their husbands."

Managing the financial burden of home-based care is another aspect that a primary-care model that can cause problems. In one instance, a financial problem was caused when a prescribed drug that a nurse went to collect at a pharmacy was not covered by the PBS safety-net, the problem being exacerbated by the family already experiencing poverty.

6.4 Use of the 1800-number

The 1800-number, and on-call nurse roster, were important components of the GAPS project, allowing the services to be available 24 hours a day, seven days a week. The reaction of patients and carers to this part of the service was positive, particularly in relation to providing after-hours support. Some were able to contrast the situation with how it had been before the project. The people who had cared for a relative prior to the establishment of GAPS expressed their gratitude to the oncology nurses who were "always there for them". However, they also were aware that only two people provided this service and that they were reluctant to phone for help in the middle of the night or the weekend. As one carer said:

"The service before GAPS was adequate, it fulfilled our needs, but you would only ring after hours if you were really on the back foot."

Another said:

"Ringing after hours was one of my biggest worries, if you had a problem at 6pm you would wait until the morning. I'd never disturb the nurses unless I had to. Most people are like that."

These people commented that with GAPS they have the awareness that a team of people do the after hours on-call work, and no single person is being overworked. They said that they would feel much more comfortable ringing after hours with this knowledge.

"I'm almost afraid to ring up and ask for anything because they always want to help."

Despite the 1800-number, some people on the current program still expressed a reluctance to ring the number for help after-hours, preferring to wait until the morning, or in one case to take the individual to hospital. In the latter case, the individual did not seem to be aware of the 1800-number, although he did have the 1800-number "fridge magnet" reminder. Some people still rang the oncology unit or the district nurses directly, without using the 1800 number, these were often long term oncology patients who had developed strong relationships of trust (and perhaps dependence) with the nurses in the oncology department.

Many of the patients were able to describe an example of a time when they used the 1800-number and the benefits of having the number to use:

"X was having palpitations and severe pain, I rang the 1800-number and they talked me through it and told me that everything would be fine. It's great to have that service here, otherwise I would have rung an ambulance and it just wasn't necessary."

"The 1800-number provides you with a safety net. Before GAPS, I was told that I could ring my GP if I had any problems, but he didn't take calls, and doesn't ring back until much later."

The 1800-number is also used within normal hours to provide a safety-net. For example, one patient who lives outside Griffith rang the 1800-number when he experienced a difficulty to notify

the palliative care services that he is coming into the GBH emergency department. The advance notice gave staff time to prepare for his arrival and the subsequent "admission" into hospital was efficient.

Five nursing staff were currently on the after hours roster to answer the 1800 calls. All the staff involved in after-hours care commented that the system of working one week in five was effective, as it allowed a continuity of care with patients, that a larger roster of people may not allow. During the nine month period from October 2001 to June 2002, there were 66 phone calls on the 1800-number, of these 34 calls were made after hours and 37 calls resulted in visits from the on-call nurses. Although the level of demand and subsequent workload on the nurses is not high, calls during the terminal stage can be frequent and may result in a period of high workload for the individual on call.

Reaction to the after-hours system among the GPs was positive. Most thought it had improved coordination (7 of 10), thought patients were less likely to present at the emergency department after-hours (8 of 10) and that there is effective communication between people providing after-hours service (8 of 10). Other respondents were unsure. However, opinions on how their workload had changed were mixed. About half of the GPs thought their workload had not changed. Three thought their workload during normal hours had decreased, while three thought their after-hours workload had increased. Analysis of the on-call data revealed that GPs made only 8 on-call visits, usually to confirm a death. This appears to represent a significant reduction in the after-hours palliative work load for GPs overall, even if some individuals perceived their workload to be higher. Nonetheless, the concerns of some GPs at the beginning of the GAPS project, who thought that their workload had the potential to increase due to their taking on of other GP's patients, have not been realised.

6.5 Views on the case conference meetings

Case conference meetings were held weekly and usually lasted for an hour. They were attended by a core of nursing staff, and at least two General Practitioners as well as the Minister responsible for coordinating the pastoral care component of the program. Each patient on the project was discussed, and was assigned a phase (stable, unstable, deteriorating or terminal). In some cases, patients who had been in the stable phase for a long period were made inactive, meaning that while they remained registered as GAPS patients, no further services would be offered until the patient requested them.

The case conference meetings demonstrated a very good degree of communication and shared decision making between the nursing and medical members of the team. The discussion between the nurses and the GPs was detailed and constructive and resulted in new plans of action. A good example was in the area of pain management, where the benefits and side effects of potential drugs were assessed from the staff's experience and their knowledge of the individual patient.

The staff at the case conferences also demonstrated a high degree of support for each other and the meetings were a means of de-briefing after difficult or emotionally demanding situations. However, more could be done to integrate the pastoral care elements of the GAPS service at the case conferences. Although the pastoral care representative was always in attendance, it appeared that he was regarded as an observer, rather than a participant with specific knowledge of particular patients.

The case conferences were not dependent on any one individual in a coordinating position to operate effectively. There was no observable difference between the meetings chaired by the coordinator and those chaired by another member of the GAPS team.

In response to the surveys, all but two GPs reported attending the case conferences (one of the non-attenders had not referred any patients, the other only two) and attended as regularly as their schedule allowed. All eight thought the case conferencing improved the coordination of services,

communication about non-clinical aspects of care, and provided opportunities to share ideas (the two non-attenders were unsure about its effect on patient care). Seven GPs thought the EPC items provided adequate payment model, though two did not.

6.6 The patient held record

The patient held record is a feature of the GAPS program which participants identified as creating important and beneficial changes to the way that their care was coordinated. The people who had looked after relatives prior to the GAPS program commented that emergency trips to the hospital often involved long periods of waiting and unnecessary tests.

"Before GAPS I had one serious problem. My husband had unbearable pain and I took him to the emergency department at the hospital. The nursing sister there refused to ring his GP and instead they made him have x-rays and blood tests at 3am. But all they had to do is to ring Dr X and he would tell them what was going on."

"Before I used to end up in emergency and wait for hours there. The pain would be so bad you would feel like throwing yourself against the walls. I always would end up talking to someone new who didn't know anything about me."

"Now my notes travel with me - they don't have to ask any questions, the whole system is steam-lined. I can come in and get my pain sorted out and then go home again."

"They know your history and you don't have to go through the whole thing every time. You don't have to go to emergency at the weekends and wait and wait. The doctors and nurses working together and keeping in touch keeps everything coordinated."

As the above quotations indicate, the introduction of the patient-held record has meant that visits to the emergency department by GAPS patients have become less stressful and more likely to meet their needs.

Patient-held records were meticulously updated by the community nurses and appeared to allow for smooth transition from one nurse to another. The nurses made an effort to involve the carers and, where possible, the patient in the composition of the results. For example, they read through and explained any technical language in the notes and also consulted carers and patients on the symptom scores such as level of pain experienced, sleep, appetite and so on. In practice, working through the symptoms scores appeared to be a very useful way of generating discussion with the patient or carer and involving them in the decisions that were being made about care.

In the survey, the eight GPs with the most referrals reported entering data into the patient held record, and rated the record as useful. The two other GPs did not enter data, and did not think it useful. There was an even split among GPs in terms of whether they thought the data were accurate or moderately accurate.

6.7 Support and information to patients and carers

The provision of information and reassurance to patients and their carers is an important part of palliative care. For example, practical advice about the care of the patient, the expected outcomes and the trajectory of the disease have been identified as very important for the quality of life of carers [Seale, 1991]. Some patients stressed the importance of GAPS in providing someone that they could talk to about their problems and raise any concerns.

"The community nurse comes in once a week. It gives you a chance to let off steam. If you have any worries you can talk to her. She puts you at ease, they are very friendly and very informative."

Others described the reassurance they had from the practical information they received about patient care:

"The nurses have been really great, teaching me how to look after X. I didn't know how to change him, how to wash his bottom and everything."

6.8 Bereavement support

The members of the volunteers program suggested that people preferred to be left alone after the death of a relative. During visits to the oncology service at the hospital, however, it became clear that bereaved relatives were frequent visitors, coming to talk with staff about the experience and to thank them for their assistance. Although the clinic was often busy, the staff took time to talk and provide tea and coffee. Some individuals became quite regular visitors. This indicates that people in the community do feel the need to maintain contact with the staff who helped them through their relatives' deaths and that bereavement support is an important, but yet to be fully developed component of the GAPS model. The coordinator of the program noting this problem commented that:

"Through the palliative care strategy we are encouraged to treat the patient and their family as the unit of care, but when the patient dies the funding stops. We often monitor patients for six months, but we don't have the resources to monitor for longer."

The lack of a social worker was raised as a reason why bereavement support was not being carried out effectively. Bereavement support, however, is an area where the people providing pastoral care and the volunteers could be used more effectively.

6.9 Support for staff after the death of a patient

Stress and burnout of palliative care staff are recognised as causing a high turnover of palliative care staff and affecting the long term sustainability of palliative care programs. Formal support and counselling for staff is an important strategy to deal with work that is inherently stressful [Pincombe & Tooth, 1996].

No formal support existed for GAPS staff after the death of the patients. Some staff said that they relied on each other for comfort and support during these times. The case conference meeting did provide an opportunity for staff to discuss the events leading up to a patients death and receive reassurance that they did all that was possible for the individual.

6.10 Volunteers and pastoral care

Pastoral care provided by volunteers and the Ministers Fraternal is described by GAPS as an important part of the model. Prior to GAPS, the Cancer Patients Assistance Society (CPAS) provided volunteer support.

Eight people attended the volunteers meeting at the Oncology Unit in April 2003. They were all women. Most of the current group of volunteers were originally recruited through the Cancer Patients Assistance Society. Most of their work involves giving people support at the oncology clinics. Others assist patients with daily errands and getting to the doctor. Few of the women are keen to do home based visits.

In addition to this group, there was one male volunteer who was working through the Anglican Church. He commented that the lack of male volunteers meant that men on the GAPS program were disadvantaged in having access to pastoral care of this kind.

The Uniting Church Minister is active in the GAPS program and is keen to extend his role in the community. Strategies should be developed to utilise his skills more effectively. There was no

formal contact between the minister and the volunteers and there appears to be the need to coordinate all the different aspects of pastoral care, which appear to be working quite independently at the moment.

6.11 Staff access to education

Education and technology to provide support and facilitate networking (Internet and email) have been identified [McConigley et al., 2001] as very important components of palliative care services, particularly those operating in rural and remote settings.

Education remains a problematic component of the GAPS model. Some of the nursing staff commented that they have not had any education organised by GAPS since the inception of the program. There was a move to develop palliative care educational materials for the staff of the nursing homes in Griffith, but this had not taken place at the time of writing. Access to educational materials in an informal manner (for example access to on line journals) is problematic for some of the staff who do not have access to a computer or the Internet.

Nursing staff complain that they have had no formal education. They comment that education appears to have taken second place to other issues:

"There are too many things going on, the CD, the conference. There is a lot of talk, but the grass roots stuff is being neglected. We have had no education, we were supposed to have basic education at the start but nothing happened."

Some staff comment that they do provide some informal education for others. For example, the Oncology nurses have provided advice to the Private Nursing Service about the use of the syringe driver.

6.12 VMO rights for GPs at Griffith Base Hospital and standardised protocols

The eight GPs who referred most patients to GAPS all took up Visiting Medical Officer (VMO) rights at the hospital, the other two did not. Only one of the eight GPs did not use this right. The majority of GPs thought VMO rights improved communication between different services, helped coordination and provided opportunities to share ideas. In relation to the impact of the protocols, there were differences of opinion among the GPs. Four GPs found them useful and thought they aided coordination while a fifth thought they aided communication about non-clinical care. The other GPs were unsure.

6.13 Access and use of computer technology

The PalCIS information system has provided a considerably richer set of data on palliative care patients and service utilisation that was previously available. The use of the palm pilots by clinicians making home visits appears not to have been feasible. As noted in the previous chapter, the individual records captured much less activity than the weekly summarises. During the three-week visit, none of the nurses were observed to enter information about the patient and their symptom scores directly into PalCIS using the palm pilot. It appears that such information is transcribed from the patient record at a later date.

Access to computers has been an issue throughout the GAPS program. At the time of writing, the Oncology nurses remained without computer access, which limited their ability to perform routine tasks such as developing work plans. Access to email and the Internet would have increased their ability to communicate with other members of the team and access educational material. In addition, although the GAPS coordinator spent considerable effort in maintaining a central PalCIS database, he was without access to a computer at various stages in the project due to hardware problems. At these times, he was not able to access important GAPS databases or provide summaries of GAPS information in a printed form to the Board of Governance.

7. Project management, governance and external relationships

7.1 Project management and governance

The project coordinator role and the Board of Governance were critical factors in ensuring the project could operate as a change-agent within the local service setting. When interviewed, many of the stakeholder representatives noted that the key motivation in instigating GAPS was to improve coordination and to develop a more coherent model that included GPs; it was not pursued because of a lack of quality care or any lack of dedication among existing staff. This gave rise to set of organisational changes that required both a way of getting buy-in by GPs and the Greater Murray AHS and its local representatives, and a 'local advocate' role which was clinically credible. The new arrangements to improve coordination could not just be add-ons to an already busy clinical schedule of patient contacts.

The new structures implemented by the project (described in chapter 4), and the resulting positive impact of patient care demonstrate the overall effectiveness of this management structure. The coordinator was able to lead and coordinate individual changes, while the Board of Governance provided a forum for stakeholders to work together on broader policy issues. The Board also provided the project with sufficient autonomy to pursue a model of care that differed from other arrangements within the Area. The new model of care affected power relationships locally, and, to a lesser extent, within the Area as a whole. These needed to be managed within a formal structure.

The role of project coordinator encompassed a number of activities, including project design and development, project management and liaison with health care and volunteer services, as well as making contributions to palliative care service developments within GMAHS. The project was fortunate to find an experienced palliative care nurse for the coordinator role.

Progress on the project was reported at the monthly Board of Governance meetings, the routine presentations consisting of an activity report from the project coordinator, and reports from the two treasurers on the budget and finances. The summary of activity incorporated quantitative output from the PaICIS system, but although the version of PaICIS being used was well suited to supporting clinical activity, it seemed less able to meet the management reporting needs that a project like GAPS requires. Comments were made in the Mid-term report on how better management information could be produced, but these appear not to have been adopted. This was partly linked to the computer hardware problems that the project experienced. The small nature of the project may also have lessened the need to summarise data into statistical form. Nonetheless, governance would have been aided if such data were available. Quantitative data on the use of emergency department services would have been particularly useful given the project aim of reducing inappropriate use of this service.

The only other administrative meeting adopted by the project was a regular nurses meeting. This was instituted to work through the issues relating to the new nursing arrangements after June 2002. By December 2002, the Board of Governance Minutes report that the meetings had been "very useful" in dealing with potential problems.

7.2 Relationship with Greater Murray Area Health Service and other stakeholders

The viability of a generalist model of care like GAPS depends not only on resources being earmarked for the model, but also on a robust local multi-disciplinary primary health care tier. One of the limiting factors for GAPS was the pre-existing pressure on both psychosocial counselling and community nursing positions within the Griffith Area. In Griffith and its surrounding localities, as elsewhere in Greater Murray, recruitment and retention of community health staff with the requisite

mix of skills is a major issue. Fortunately, the GP population within Griffith was of a reasonable size and remained stable throughout the project. A small increase in the number of GPs within the surrounding towns also enabled the planned expansion of the project to proceed.

As noted above, the adopted management structure gave GAPS a degree of autonomy within which to operate. This was necessary for it to confidently implement changes to the operation of services. The project was given high-level support from within the GMAHS to pursue this agenda, and a Area-coordinator for the NSW Complex and Chronic Care program was a member of its Board of Governance.

But, apart from this participation, links to other palliative care services within the Area were limited. Although some nurses initially sought support from the Mercy palliative care services in Albury, a stronger relationship between GAPS and the Mercy Hospital was not pursued at a project-level. While understandable in the early stages of the project, given the internal changes to be implemented, the project perhaps missed an opportunity to tap into a source of expertise by not establishing a formal link. Instead, the project developed links with the South West Sydney palliative care service. This linkage appeared to have been useful but was based on personal relationships rather than a structural approach.

Another consequence of this internal focus was a limited understanding of the project across these other services, and a limited appreciation of its benefits. For example, the Blueprint for Change that launched the State program in 2001 mentioned the GAPS project as an example of good practice [NSW Health, 2001b]. This reflected the visibility of the project at an early stage of its implementation. But this Statewide document, and the subsequent draft of the GMAHS strategic plan for palliative care [GMAHS, 2002b], did not situate the GAPS model within the context of other models and organisational arrangements, nor did they discuss how a model such as GAPS could be developed further. This may be a threat to the sustainability of the project in the long-term, and has some parallels to the position of the Commonwealth Coordinated Care Trials.

In some respects, the relationship between GAPS and the Area as a whole is complicated by the current placement of palliative care within the Complex and Chronic Care program. This is not a natural position for it. This NSW program covers a broad spectrum of services such as rehabilitation and cancer care as well as palliative care. Its reporting requirements are consequently large. The GAPS project adopted a series of 50 performance indicators in order to meet these requirements. Given the size of the project, and its focussed aims, this was clearly excessive and is unlikely to be informative.

Despite the comparatively limited growth of links between GAPS and the broader GMAHS, the project received recognition and support from various other sources. Palliative Care NSW approached GAPS about organising the Annual State Conference in Griffith. In addition, the Federal Minister for Health, the Hon Kay Patterson, officially launched the Coleambally expansion on 9th April 2003.

8. Conclusion

8.1 Outcomes of the project for patients and local services

For the people of Griffith, the changes made to the organisation of palliative care services during the GAPS project have brought a notable improvement in quality of care. In particular, patients are no longer presented with a fragmented service and variable after-hours coverage. The implementation of the GAPS model of care has resulted in important benefits to patients:

- Expanding the service from one being mainly focussed on cancer patients to one that includes people with a range of terminal diseases, such as motor neurone disease and multiple sclerosis;
- Services being available on a 24-hour, 7-day basis, thereby providing an appropriate safety-net to deal with potential patient emergencies, as opposed to patients using the Griffith base hospital emergency department. Emergencies are recognised as a problematic part of providing predominantly home-based care [O'Neill & Rodney, 1998];
- Improved coordination of services that provides patients with greater continuity of care, wasting less of their time and avoiding unnecessary diagnostic work. The multi-disciplinary approach means staff work together to meet patient needs in the best way possible.

The model has also been of benefit to clinicians. The multi-disciplinary approach has provided clinical staff with mutual support, particularly at the case conference meetings, and has stimulated greater understanding and respect across the professional disciplines. The case conferences have worked well, and there was no apparent change between meetings run by the project coordinator and those run by other members of the team, which is promising in terms of the long term future of this part of the model of care. The new on-call arrangements also appear to have reduced the after-hours workload for general practitioners overall.

The essential elements of the GAPS model appear to be:

- (1) The weekly case conferences,
- (2) The 1800 number and on-call nursing roster,
- (3) The patient held record, and
- (4) The shared protocols and procedures.

But these have been supported by other important elements and, until tested, it is unclear to what extent their absence might hamper organisations implementing a similar generalist model of palliative care. These elements include:

- The common assessment instruments used to rate patient well-being;
- Administrative support for general practitioners to coordinate the uptake of EPC items;
- A computerised information system that collected patient health status information as well as service utilisation data;
- Community awareness program (in this instance, including television advertising).

For the project itself, the appointment of a project coordinator and Board of Governance were also seen by staff and stakeholders as an important (and for some an essential) component. The new model of care represented a substantial change in work practices, not only within organisations but across organisations.

The local stakeholders invested considerable time and resources into planning the implementation of the new model. Yet any change is likely to have unforeseen effects, as well as those desired, and this requires stakeholders to have faith in their plans and commitment to tackle problems as they arise. The program coordinator, and the representatives of the GMAHS and the Murrumbidgee Division of General Practice, share with the frontline clinical staff credit for implementing a locally feasible model that represents an improved service to the local community.

The challenge for the GAPS project remains its extension to smaller populations around Griffith. The timetable of expansion did not allow the evaluation to assess the impact of the model of care on patients in these areas, nor how difficulties posed by serving small towns were overcome. Initial reports were positive but these were only preliminary.

Although the project has improved services overall, the project has yet to tackle all the issues that it had hoped to address. These include providing greater support for bereaved relatives and friends, providing educational material and facilities for staff, making pastoral care more integrated into mainstream services, and expanding the role of volunteers. Solutions to some of these issues are not easy to implement, being dependent upon factors that the project has little potential to influence. For instance, the provision of bereavement support would have been helped had it been possible to recruit a social worker. But in Griffith and its surrounding localities (and no doubt in other rural areas), recruitment and retention of community health staff with the requisite mix of skills is a major issue, even where there is already a critical mass of population. The problem is even greater in smaller populations and where a generalist approach is preferred because there are few viable alternatives.

Nonetheless, it is disappointing that greater progress was not made in relation to staff education, and perhaps this represents the opportunity cost of activities like making the CD-ROM about how to run a GAPS-like project, shooting the promotional video, and arranging the NSW palliative care conference. Similarly, it was surprising that resources could not be found to improve access to technology such as computers, email and the Internet. Some sections of the GAPS workforce still have no computer access, and this limits their communication with the team, and their ability to keep in touch with important developments via the Internet.

Finally, information on service activity that would be expected for monitoring a mainstream service was not produced from the computer system as envisaged. This was partly a limitation of the version of PalCIS software used by the project, and may be rectified in later versions. It was also linked to computer hardware problems that the project experienced. A notable limitation was the inability to provide longitudinal activity data in graphical form (as in Figure 5). Providing such information would have aided the Board of Governance, and provided an incentive to improve the completeness of the data. The lack of quantitative data on emergency department visits was also a notable omission, given the expressed aim of the project to reduce its inappropriate use. Nonetheless, these issues are minor and, overall, the project and the relationships among the stakeholders seem to have been managed very effectively.

8.2 Project sustainability

The implementation of the GAPS model of care has required the commitment and dedication of many people. In addition to the change in work patterns, and the new demands of the case conferences, staff have regularly attended GAPS meetings associated with its governance or planning. For example, staff volunteered an evening after work, to outline their perceptions of GAPS for the promotional video. GAPS has been sustained by the enthusiasm of its participants, and has been allowed a considerable degree of autonomy within the Area Health Service. It also received substantial funding from the State and Commonwealth. The challenge for the project now is how can it be sustained.

It is clear that staff on the project would like it to become mainstream. There is also support for this within the wider community. Television advertisements, and the involvement of well-known local people in the governance of the project has given the project a high-level of community awareness, although these are perhaps secondary to the positive experiences of GAPS patients and carers in terms of influencing community opinion.

In relation to service provision, the essential elements in the GAPS model of care require little additional recurrent funding from fixed budget sources. The involvement of general practitioners in case conferences, the GP on-call roster, and hospital activity was funded using MBS items. The cost of the on-call nursing service was relatively small.

A key issue for the project, and any similarly funded project, is the long-term role of the project coordinator. The position was funded from the Commonwealth project funds, together with additional funds from the State. The coordinator played a key role in managing the process of change across the various organisations. These funds are not ongoing, and the local services will either have to find a long-term funding source, or the role will need to evolve. From our perspective, there are various reasons why the role needs to change, but the most compelling reason arises when one considers a widespread implementation of the GAPS model of care. This simply cannot be accompanied by the creation of many coordinator positions; the opportunity cost of creating these essentially administrative positions would seem excessive. This cost is borne both in terms of funds required and the loss of clinical staff to an essentially management position, something which should not be a consequence of such projects.

There is a reasonable chance of GAPS being able to operate with a reduced coordinator role. First, the major responsibilities of the coordinator were associated with designing and organising the new care structures and collaborations. These are now mostly in place. Second, although the coordinator played a key role in chairing the case conferences, it seems that the experience gained by others over the course of the project means that this role can be allocated to other people. Third, to become mainstream, the management of GAPS needs to become more embedded in existing management structures. This is not straightforward, of course, given the multiple service providers involved. The Area responsibility for providing palliative services, as outlined in NSW Health policy, suggests that the Area Health Service should take the lead role. It is also responsible for running the public hospital and community nursing services, and has the capacity to pick up much of the project administration. As such, we believe that the ending of funding for the coordinator role need not threaten the sustainability of GAPS in particular, or its generalist model of care.

Similarly, the project Board of Governance needs to evolve into a more permanent forum for stakeholders. Cooperation between GMAHS, the general practitioners, and other primary care services is in the interest of the local community across a number of health issues, not simply palliative care. Moreover, while the Board of Governance gave the project sufficient autonomy to create a sense of ownership and mutual support, it may have also resulted in links to other palliative care services within the GMAHS not to be been utilised as much as possible. In the long-term, palliative care services need to be coordinated on a regional basis and these links need to be strengthened.

There are some potential threats to the long-term sustainability of GAPS. The main local threat involves the demands placed on community nursing staff. The community nurses, who are responsible for home visits during the day, commented that their workload prevents them from spending the amount of time with individuals that some need. This is particularly evident in terms of being able to provide bereavement support. They also described difficulties in juggling priorities between GAPS and other patients. The nurses often showed high levels of exhaustion and strain. Currently, enthusiasm for the project is suppressing the effect of this demand, but sustainability cannot be built on enthusiasm. It seems desirable to revisit the decision to restrict day visits only to community nurses, and not include oncology nurses. The decision reduced the workforce available to meet this patient demand. It also limited the exposure of the oncology nurses, who are on the on-call roster, to patients in their normal environment.

This is unlikely to be helpful when they are on-call. The general message for other projects in this is to consider how resources can follow patient demand when considering changing work patterns.

Another threat stems from the wider policy environment. Palliative care services are currently placed within the NSW Health Complex and Chronic Care program. This is imposing management requirements that are burdensome, and is underpinned by a philosophy based upon a specialist approach to care. A rigid pursuit of this policy at an Area level is likely to place a severe strain on services at a local level.

Included as Appendix 6 is the final sustainability assessment of GAPS. This assessment has been included in each of the two previous reports as a tool to monitor progress in the likely sustainability of the model. With a final score of 22 out of 30, GAPS has a high level of potential sustainability.

8.3 Generalisability of the GAPS model of care

For towns the size of Griffith, with around a dozen GPs, a regional hospital and community services, there appears to be no reason why the GAPS model of care could not be adopted. Such locations should have sufficient resources and clinicians to support the essential structural elements within the model of care (the case conferences, the 1800-number and on-call nursing roster, the patient held record and shared protocols).

For smaller towns, these features would also seem to be workable, though they would need to be tied into a larger area so that on-call/after-hours work was shared. This is the model being progressively implemented by GAPS, and there are no obvious reasons why it should not succeed.

The generalisability of a GAPS model of care becomes more problematic within larger population centres. Structurally, it is likely to require a population to be split into zones. For example, the GAPS model relies on weekly case-conference meetings that last a reasonable duration (approx 1 hour). But with larger population centres, there may be a greater variety of structures to provide 24-hour, 7 day access to services. Larger hospitals may offer specialist services, and so might be the natural vehicle to provide on-call services. Moreover, while involvement of general practitioners is fundamental to a multi-disciplinary approach, and is highly desirable, the incentive of reducing their on-call workload may not be so great. For example, in some areas, GPs have already organised cooperative arrangements to share this workload.

Of more concern are the potential discrepancies between a primary-care led service and a specialist State-funded service in terms of costs to patients. Patients treated by a service based on general practice face the prospect of increasing co-payments payments (for privately provided medical, diagnostic and pharmaceutical services) in contrast to public patients of a specialist palliative care service who are unlikely to face such co-payments. This raises the prospect of considerable inequality.

That said, the provision of a State-funded specialist palliative care service is not a realistic option for the multitude of small, rural communities that are spread out over vast distances in Australia. The GAPS model, with its primary care and multi-disciplinary approach, is a quality alternative.

Appendix 1

Roles of palliative care services within Australia

Role Delineation

Individual States and Territories have developed their own systems for classifying various levels of palliative care services available to communities within a region. As there is no single classification, the descriptions below were developed during the Australian National Sub-acute and Non-acute Patient Classification (AN-SNAP) Study completed in 1997. They represent an attempt to amalgamate the various definitions in used across Australia into a single set of role delineators.

Level 0

No service

Level 1

Primarily supportive. Management and /or care planning/consultation by general practitioners and community nurses (community patients). Non-designated beds (inpatients). Consultation available as required from medical practitioner specialising in palliative care, clinical nurse consultant in palliative care and/or allied health staff. Continuing staff education programs in palliative care available.

The GAPS model would be classified as a Level 1 palliative care service.

Level 2

As Level 1 plus designated multi-disciplinary palliative care team. Specialist community palliative care service that includes mobile consultancy support from medical practitioner specialising in palliative care (community patients). Hospice or designated palliative care beds managed by medical practitioner specialising in palliative care (admitted patients). Pastoral care and bereavement support provided. Designated allied health staff are an integral component of the service. Access to bereavement counselling service.

Level 3

As Level 2 plus integrated community and/or hospice and/or hospital consultative service under direction of medical practitioner accredited in palliative care or palliative care physician. Has medical officer or medical registrar. Specialist nursing staff with post basic qualifications and experience in palliative care rostered 24 hours. Has links with oncology, radiotherapy, anaesthetics, psychiatry, multi-disciplinary pain clinic, rehabilitation and surgical services. Palliative care specialist providing formal consultation liaison to other services. Conducts formal teaching and research.

Palliative Care - Modes of Delivery

Whatever the differences in the definition of role delineation, the level of palliative care services available will be composed of mix of specialist providers, generalist providers and support services in both the public and private sectors. Services are provided across inpatient, outpatient and community based settings through a combination of the modes of delivery listed below:

- (a) Designated hospice services;
- (b) Designated palliative care units in acute hospitals;
- (c) Designated palliative care units in sub-acute hospitals;
- (d) Non-designated palliative care services in acute or sub-acute hospitals;
- (e) Admitted same day palliative care hospital services;
- (f) Palliative care hospital outpatient clinic services;
- (g) Specialist palliative care community services;
- (h) Generalist community based services.

A brief outline of each mode of delivery is provided below.

(a) Designated hospice services

These Level 3 services tend to be located in larger capital cities ranging in size from 20 - 80 designated palliative care beds. They represent a significant proportion of expenditure on inpatient palliative care services. The demand for palliative care services does not warrant the operation of hospices outside larger Australian capital cities. There are approximately 12 designated hospices currently operating in Australia.

Hospices are owned and operated by both public and private sector organisations. Hospices in the private sector are sometimes owned by religious organisations and often receive funding from State health authorities.

(b) Designated palliative care units in acute hospitals

These may be Level 2 or Level 3 public sector services and are usually located in capital cities and larger regional centres. Hospitals in capital cities (including teaching hospitals) sometimes operate designated palliative care units and in other cases refer palliative care patients to a hospice or palliative care unit in a sub-acute facility. Larger regional centres, typically with a 'base' hospital of more than 120 beds, usually operate designated palliative care units with between 6 and 15 beds. There are about 20 such units in both Victoria and NSW.

(c) Designated palliative care units in sub-acute hospitals

These are usually Level 2 public sector services and tend to be located in capital cities and larger regional centres. The structure of sub-acute inpatient facilities varies between States. However, most capital cities operate at least one major sub-acute hospital that provides a significant palliative care role. Typically, these services would operate between 30 and 50 palliative care beds.

Similarly, larger regional centres frequently operate designated sub-acute facilities that provide a range of palliative care, rehabilitation and geriatric evaluation and management services. Typically, these facilities operate between 5 and 30 palliative care beds.

(d) Non-designated inpatient palliative care services in acute and sub-acute hospitals

These are generally Level 1 public sector services and are provided where designated palliative care units do not operate. In many rural and remote parts of Australia, these services represent the only hospital based palliative care service.

In principle, these services have access consultation services from specialist medical, nursing and allied health providers. In practice, however, the level of support available varies significantly depending on the location of the hospital and the organisational structure in place in the jurisdiction. In NSW for example, a palliative care medical clinician travels regularly to Dubbo to provide specialist palliative care services to a local sub-acute facility with between 5 and 10 non-designated palliative care beds.

(e) Admitted same day palliative care services

Admitted same day palliative care services are provided in most States and Territories generally as part of a wider program of palliative care services. These services may provide specialised nursing care or services for people who need company and/or advice on how to cope with their illness. They may also provide respite for carers of palliative patients. Patients may be referred to these services either from inpatient units or from the community.

(f) Palliative care hospital outpatient clinic services

Palliative care hospital outpatient clinic services tend to provide allied health services and are generally provided as part of a wider program of palliative care services. They may also include bereavement counselling and support services for family and carers.

(g) Specialist palliative care community services

Specialist palliative care community services operate in all States and Territories in both the public and private sectors. Services are provided in a person's home by specialist palliative care clinicians comprising nursing, medical and allied health staff.

- Nursing Services

Nursing staff (clinical nurse consultants and registered nurses) represent the majority of specialist palliative care community practitioners. In most States and Territories, these services are located within community health centres. However, there are significant variations in both the way these services are structured and the way that they interact with other community based services.

In some cases, specialist palliative care nurses provide a consultation service supported by generalist community nurses who provide direct patient care. In other cases, specialist palliative care nurses provide direct patient care. Regardless of the service delivery model, specialist palliative care nurses collaborate closely with generalist community nurses.

Many NSW Area Health Services, for example, work under a generalist primary care model in which community based nurses provide services within defined geographical boundaries. Within these boundaries, some nurses provide additional specialised resource roles (such as specialised palliative care services) that compliment the skills of other colleagues in their respective teams. In contrast, some NSW Area Health Services operate under a model whereby specialist palliative care nurses operate as discreet teams, generally with one to five members.

- Medical services

Specialist medical services for community patients are typically provided by hospital based medical practitioners specialising in palliative care. These services usually operate around a

referral based consultative service that assists general practitioners and community nurses with palliative care management. Community health centres do not typically employ medical practitioners specialising in palliative care.

- Allied health services

Specialist allied health palliative care staff are normally hospital based and occur in Level 2 and level 3 public sector care services in metropolitan areas. Typically, they comprise psychosocial clinicians working as part of a multi-disciplinary palliative care team rather than staff who are part of an allied health department. They include a mix of psychologists, social workers, counsellors and pastoral care.

Other allied health disciplines may also provide assessment and treatment services. For example, speech pathologists treat swallowing dysfunction and occupational therapists provide equipment prescription and home modification assessments.

(h) Generalist community based services

Generalist or primary health care practitioner services operate in all States and Territories in both the public and private sectors. In rural and remote areas in particular, they are often the primary care providers for palliative care patients. Services are usually provided in a person's home by general practitioners, generalist community nurses and to a lesser extent, allied health staff.

- General Practitioner Services

General practitioners are frequently the principal primary carer for palliative care patients. Their specific role general practitioners varies depending on the model of care in operation for a particular patient population. They may maintain full medical care of a patient with access to consultation/liason services from a specialist palliative care service. Alternatively, care may be formally shared between a general practitioner and a specialist service or finally a general practitioner may hand over responsibility for the care of a patient to a specialist palliative care service.

- Nursing Services

Generalist community nurses in the public and private sectors provide nursing services to palliative care patients in all States and Territories and across both metropolitan and rural and remote areas. As noted generalist community nurses work in close collaboration with specialist community palliative care nurses where these services exist.

In metropolitan areas, generalist community nurses in the public sector typically operate as part of a Level 2 or Level 3 integrated hospital/hospice/community palliative care service. In rural and remote areas, generalist community nurses are more likely to receive consultation/liason services from visiting specialist medical and nursing clinicians. Generalist community nurses usually liaise closely with patients' general practitioners but typically would do so more in rural and remote areas where limited specialist palliative care services are available.

- Allied Health Services

Community based allied health staff operating in discipline specific teams (such as social work or psychology) provide services to palliative care patients where specialist services are not available. This occurs in Level 1 and Level 2 services and is the usual mode of service rural and remote areas. The services provided are similar to services provided by specialised community based allied health staff.

Appendix 2

National Framework Objectives and Strategies relevant to the GAPS project

This appendix summarises the relevant objectives and strategies that the GAPS project aimed to met. Objectives marked with * were not in scope for the current study (because they were too ambitious for the current project). All other objectives are in scope.

Objective 2.4: Service development

To promote ongoing evaluation and research into patient care needs, best practice palliative care, service delivery models, and resource allocation models; and to implement the results of such research.

Strategies

- 2.4.1 Develop population benchmarks to guide palliative care service provision, taking into account rural and remote area needs. *
- 2.4.2 Support the development and implementation of best-practice guidelines and clinical pathways in palliative care.
- 2.4.3 Develop service models that:
 1. deliver timely access to appropriate services, integrated care across all palliative care settings, continuity of professional carers, and flexibility to meet changing patient and carer needs over time; and
 2. provide for consultancy support to all health care practitioners caring for people who are dying.
- 2.4.4 Develop flexible service models for delivery of palliative care (including consideration of the potential role of health care delivered through information technology) to suit the specific requirements of communities with:
 1. particular needs related to geography, especially rural and remote communities;
 2. specific clinical and social needs, including children with life-threatening illness; people with mental illness, late-stage dementia, HIV/AIDS, chronic airways limitation, or progressive neuromuscular conditions; and any other group with specific needs.
- 2.4.5 Support the development and implementation of flexible service models for delivery of palliative care to meet the specific needs of Aboriginal and Torres Strait communities.
- 2.4.6 Develop and support the implementation of flexible service models for delivery of palliative care to meet the specific cultural and linguistic needs of groups within the Australian community.
- 2.4.7 Monitor and evaluate new models of service delivery.

Objective 3.1: Partnerships in care coordination

To support the coordination of care for the person who is dying and their family, through partnerships between the person, the family, and the service providers and volunteers involved.

Strategies

- 3.1.1 Develop and promote care planning protocols that support the family as the primary carers and ensure continuous review and monitoring of the support needs of family care providers.

- 3.1.2 Develop and promote the establishment of care planning agreements with each family of care at the commencement of care, and with regular review throughout the episode of care.
- 3.1.3 Promote and support the role of the person who is dying and the family of care as coordinators of home-based palliative care, particularly through development and promotion of the use of patient-held care records.

Objective 3.2: Partnerships in service planning and delivery

To develop strong partnerships between palliative care service providers, other health service providers, and the service system infrastructure, including administrative arrangements, to ensure the delivery of palliative care that is geographically accessible and integrated across service delivery settings.

Strategies

- 3.2.1 Promote the establishment, within each jurisdiction, of administrative arrangements that promote and support the delivery of integrated and accessible palliative care services, through resource allocation arrangements, accountability and reporting arrangements, and collaboration between central administrations and service providers. *
- 3.2.2 Develop and support partnerships between rural health providers and health organisations, and other organisations and networks within rural communities, to optimise support and care for people who are dying and their families within the local community.
- 3.2.3 Develop and promote the provision of specialist palliative care consultancy support to primary and specialist health care providers involved in care for people who are dying and their families, regardless of diagnosis, setting or geographical location.
- 3.2.4 Establish effective and coordinated information and referral services for palliative care relevant to each jurisdiction or region and accessible to patients, health service providers and the general community.
- 3.2.5 Develop service models and service partnerships that achieve coordinated care for people who are dying and their families, and promote the implementation of such models by specialist palliative care providers and all other health services and health professions relevant to the provision of palliative care.
- 3.2.6 Develop and support the involvement of volunteers in providing support services needed by people who are dying and their families. This includes volunteer orientation and ongoing training programs, supervision and professional support for volunteer workers, and administrative and resource arrangements to recognise the role of volunteers.
- 3.2.7 Develop and promote the provision of staff support programs that include personal support, counselling, debriefing, optional rotations between settings of care, and skills development.

Appendix 3

The qualitative research design

Maintaining quality of life is a key component of palliative care, but it is difficult, both ethically and practically to explore how palliative care influences the quality of life of patients and their carers. Some authors, for example Kritjanson et al. [1994] consider that research should not be conducted with palliative patients at all, as the ethical considerations outweigh the usefulness of the data collected. Standard qualitative methods such as interviews may be too emotionally and physically burdensome for patients. Lawton [2000], for example, found that patients were often unable to conduct extended conversations.

Research that focuses on carers' (often retrospective) accounts and those of nursing and other health professionals, however, may not capture important quality of life issues for the patient. McPherson and Addington-Hall [2003] found that proxies were not able to accurately reflect patient experience of level of pain, and their thoughts and feelings.

To overcome the difficulties and ethical problems of interviewing palliative patients, but still wishing to involve them in the research, an ethnographic approach was utilised. This approach has been used successfully in several major international studies of palliative care [Barnard et al., 2000; Lawton, 2000]. These researchers undertook long term studies, where they immersed themselves in the lives of the patients, a participant observation approach utilised by social anthropologists. These studies demonstrated that they could obtain detailed information about the patient and carer experience with minimal burden.

The aim of the qualitative component of the GAPS evaluation was to find out how the model of care worked for the patients, carers and staff. In order to be in a position to make these observations, non-threatening relationships based on trust and transparency of purpose had to be developed. Initial research focused on building relationships with the GAPS staff and ensuring that they were kept informed the purpose and progress of the research as well as encouraging them to have their say about the project.

As the program was largely delivering home-based care to patients, access was a key issue. The GAPS staff were effectively gatekeepers to this group. It was only in the last phase of the research, after sustained contact with the GAPS staff over a period of a year, that it was appropriate to ask them if I could accompany them on their home visits and observe their interactions with GAPS patients and their families. Letters were taken to all GAPS clients explaining the research, and consent was obtained by GAPS staff prior to any visits taking place.

The ethnographic component of the research was carried out over three weeks in March and April of 2003. It involved becoming immersed in the daily activities of the GAPS project. In addition to visiting patient's homes, time was spent at the oncology clinics, visiting patients temporality in hospital and attending the weekly case conferences where each patients' needs were discussed.

Appendix 4

Definitions of Palliative Care Phases

(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 multi-disciplinary 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

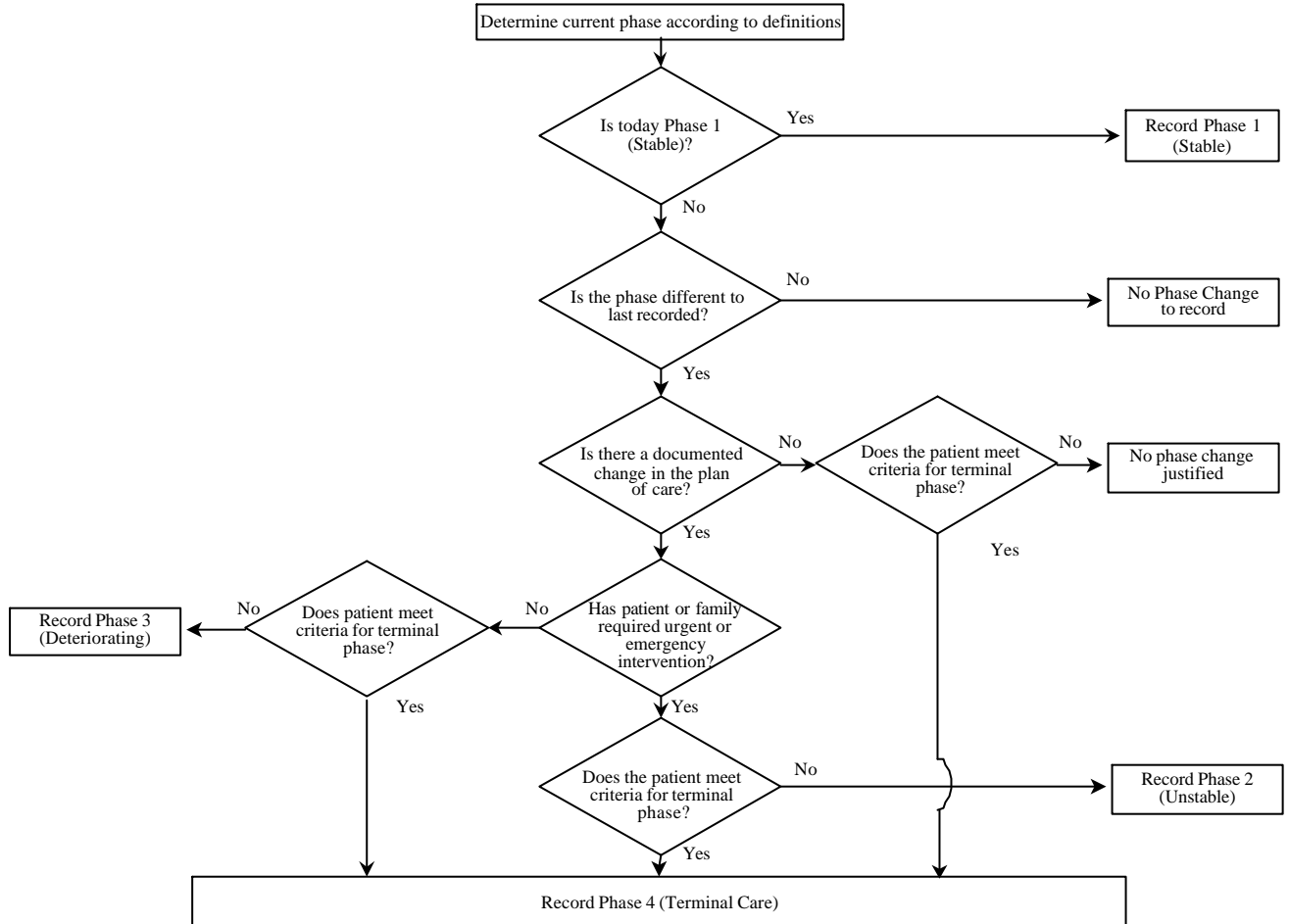
Death is likely in a matter of days and no acute intervention is planned or required. The typical features of a person in this phase may include the following:

- 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.

Palliative Care Phase Algorithm



Version 1.0

Appendix 5

Questionnaire sent to Griffith General Practitioners

General Practitioners' perceptions of the Griffith Area Palliative Care Service (GAPS).

Confidential

General practitioners play a very important role in the Griffith Area Palliative Care Service. The Centre for Health Service Development, The University of Wollongong is evaluating GAPS. As part of this evaluation, we have designed this questionnaire to explore your perspectives of GAPS.

Your participation in this survey is voluntary, and your responses will be anonymous. If you have any questions regarding this survey please direct them to Kate Senior or Alan Owen at The Centre for Health Service Development.

Phone: (02) 4221 5282 or (02) 4221 4763

Email: Kate_Senior@uow.edu.au or Alan_Owen@uow.edu.au

Thank you for taking time to complete this survey.

Section A: General Practitioner Profile

1. What is your gender? Female Male
 2. What is your age? 30yrs or under 31-40yrs 41-50yrs over 50 years
 3. Do you work full time or part time? Full time Part time

Section B: Targeting and referral of patients to GAPS

4. Since GAPS began how many patients have you referred to the GAPS program? _____
 5. How many of these patients were included in the GAPS program? _____
 6. Do you think that you had clear guidelines as to which patients could be included? Yes No
 7. If **No**, how do you think that the referral process could be improved? _____

8. Please state if you agree or disagree with the following statements

- a. *GAPS is best limited to patients with cancer* Agree Disagree Unsure
 b. *GAPS is doing what the Oncology Unit has always done* Agree Disagree Unsure
 c. *It is best that the GAPS model incorporates patients with a range of terminal diseases* Agree Disagree Unsure
 d. *The GAPS program could do more to involve patients who have other terminal diseases* Agree Disagree Unsure

Section C: Elements of the GAPS model

The case conference

9. Do you attend the GAPS case conferences? Yes No
 10. If **yes**, how often do you attend?
 a. *Only when my patient is being discussed*
 b. *As regularly as my schedule allows*
 11. Do you think that the EPC items provide an adequate payment model for participation in the Case Conferences? Yes No
 12. Do you think the GAPS payment model will work elsewhere? Yes No Unsure
 13. If no, why not?-----
 14. Has the case conference improved the following aspects of patient care:
 a. *Coordination of the clinical service* Yes No Unsure
 b. *Communication with non-clinical aspects, e.g. pastoral care* Yes No Unsure
 c. *Opportunities to share ideas about patient care* Yes No Unsure

The patient held record

13. Do you enter data on the Patient Held Record? Yes No

14. In general, how would you rate the accuracy of the information on the Patient Held Record ?

Accurate Moderately accurate Not accurate

15. In general, how would you rate the usefulness of the Patient Held Record?

Useful Moderately useful Not useful

VMO rights at the hospital

16. Do you have Visiting Medical Officer rights at the hospital? Yes No

17. How often do you use your VMO rights at the hospital?

Frequently Occasionally Never

18. Has access to VMO rights improved the following aspects of patient care?

- a. Communication between different aspects of the service Yes No Unsure
- b. Coordination of the clinical service Yes No Unsure
- c. Opportunities to share ideas about patient care Yes No Unsure

Standardized protocols

19. Have the standardized protocols (policy & procedure manual) improved the following

- a. Coordination of the clinical service Yes No Unsure
- b. Communication with the non-clinical aspects of the service e.g. pastoral care Yes No Unsure
- c. Do you find the standardized protocols useful? Yes No Unsure

Education

20. Has the GAPS program provided you with continuing medical education in palliative care? Yes No

21. If **yes**, has any education you have received helped your clinical practice Yes No

22. What method works best to provide this education? (tick as many as apply)

- a. Workshops with visiting specialists
- b. Access to on line information
- c. Conferences
- d. Other please describe-----

After hours/Roster system

23. Has the after After Hours Roster improved the following aspects of patient care

- a. *The after hours roster system has improved the coordination of care provided to patients*
 Agree Disagree Unsure
- b. *Patients are less likely to present at the emergency department after hours*
 Agree Disagree Unsure
- c. *There is effective communication between those people involved in providing after hours services*
 Agree Disagree Unsure

Section D: Workload

24. How would you describe your palliative care workload since the implementation of GAPS:

Normal Hours	Comments	After Hours	Comments
Increased	<input type="checkbox"/>	Increased	<input type="checkbox"/>
decreased	<input type="checkbox"/>	decreased	<input type="checkbox"/>
Stayed the same	<input type="checkbox"/>	Stayed the same	<input type="checkbox"/>
Difficult to tell	<input type="checkbox"/>	Difficult to tell	<input type="checkbox"/>

Section E Perspectives on patient and carer impact

25. In your opinion what impact has GAPS had on patients?

	Improved	not improved	unchanged
a. <i>Access to services</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. <i>Coordination of services</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. <i>Less duplication of services</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. <i>Continuity of services</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. <i>Pain control</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. <i>Information</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. <i>Holistic care</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. <i>Pastoral Care</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26. In your opinion what impact has GAPS had on carers?

	improved	not improved	unchanged
a. <i>Information</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. <i>After hours care/advice</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. <i>Access to equipment</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. <i>Pastoral Care</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. <i>Bereavement support/counseling</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section F: Governance & sustainability

27. Please state if you agree or disagree with the following statements

- a. *I am kept informed of the decisions made about GAPS by the board of Governance.*
- b. *The board of Governance is essential to the operation of the GAPS model*
- c. *The coordinator role is the key to making the GAPS program work*
- d. *Being paid for Case Conferences is essential to my involvement*

Section G: Further Comments

Please feel free to comment on any other aspects of GAPS that have not been covered in the questionnaire.

Appendix 6

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

In the two previous reports, a sustainability rating indicator, developed for assessing programs in health promotion [Hawe et al., 2000], was adopted to give a simple overview about the sustainability of the GAPS project. This was primarily used because of the limited information then available and was considered indicative only. The rating indicator has been completed in this final report, but it should be viewed as secondary to the material contained in the main body of this report.

The indicator consists of a checklist of questions, with each item being rated using the following scale:

2 = yes, fully
1 = yes, in part

0 = no
DK = don't know

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.

In this final assessment, the project was judged to have maintained a high level of potential sustainability (see Table 13), although our experience since the Mid-term report produced a slightly lower rating than previously. Two items related to the survival of the program (8 and 9) have been scored lower, as has item 5 on the training of people in the program. Item 2, about whether the program has shown itself to be effective, was scored higher, being given the maximum value.

Table 13 Sustainability Assessment

The first set of items concerns program design and implementation				
1. People with a stake in the program – administrators, funders, 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 relate to the broader community environment which affect how long programs last				
12. There is a favourable external environment for the program, that is, the values and mission fit well with community opinion, and the policy environment.	2	1	0	DK
13. People in the community, or other agencies and organisations, will advocate for and maintain a demand for the existence of the program should it be threatened.	2	1	0	DK
14. Organisations that are similar to the intended host organisation have taken the step of supporting programs somewhat like your program.	2	1	0	DK

Note: Shaded cell represents score for each statement.

TOTAL SCORE: 22 (maximum possible is 28)

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