

2007

# GAPS revisited: follow up evaluation of an Australian rural palliative care service

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## Publication Details

Masso, M. R., Fildes, D. L., Quinsey, K. & Matete, S. (2007). GAPS revisited: follow up evaluation of an Australian rural palliative care service. *Progress in Palliative Care*, 15 (5), 233-239.

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# GAPS revisited: follow up evaluation of an Australian rural palliative care service

## **Abstract**

The Griffith Palliative Care Service (GAPS) commenced in 2001 as a project to improve palliative care in the town of Griffith. At project completion, some elements of service delivery established by the project were sustained and have remained in place, albeit with changes, since that time. Formal evaluation was undertaken in 2003. This paper reports on a follow-up evaluation in 2006. A total of 137 people were referred to GAPS between March 2003 and March 2006, with the majority of patients in the stable phase on referral. There is evidence that the service has been able to extend its reach to people with non-malignant conditions but some elements of the service have not been maintained, including use of common clinical assessment tools as a 'common language'. The most effective elements of the service are weekly case conferences and an on-call service for those enrolled in GAPS. Both have become part of day-to-day practice, achieving an excellent level of sustainability. There is also continued support and involvement of GPs. There has been a move away from a primary care model but a stable pattern of service delivery has been maintained.

## **Keywords**

follow, up, service, evaluation, australian, rural, palliative, gaps, care, revisited

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# ORIGINAL ARTICLE

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## GAPS revisited: follow-up evaluation of an Australian rural palliative care service

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**Keywords:** *Delivery of health care, health services research, palliative care, patient care team, rural health services*

This paper reports on an evaluation of the palliative care service in Griffith, a rural town in New South Wales, Australia. In 2001, the Griffith Area Palliative Care Service (GAPS) project commenced with the aim of improving the provision of palliative care in the local area. The project centred on implementing a range of strategies to support service delivery by generalist providers, including weekly case conferences, an after-hours call service, admission rights for GPs to the local hospital, use of a patient held record, use of common tools for patient assessment and on-going management incorporated into a computerised patient information management system. This was supported by a Board of Governance and full-time project officer co-ordinating the project. Further details regarding the project have been reported elsewhere (1).

Evaluation of the GAPS project identified a number of improvements to service delivery, including better continuity of care, more efficient use of time and reduction of unnecessary diagnostic work. The most successful interventions were weekly case conferences, the use of an after-hours call number (for patients and carers), an on-call nursing roster, a patient-held record and shared protocols and procedures. The multidisciplinary approach provided clinical staff with mutual support, particularly at case conferences, and stimulated greater understanding and respect across the professional disciplines. The on-call arrangements reduced the after-hours workload for GPs. The appointment of a project co-ordinator and Board of Governance were seen as important (and for some, essential) components of the project (2).

The work in Griffith prompted the Australian Government to fund the Rural Palliative Care Program to test the model of service delivery in eight different locations around Australia, which has resulted in further reports in the literature (3,4). The model developed in Griffith has effectively become the exemplar for current work to improve palliative care in rural Australia and, together with the Rural Palliative Care Program, is well-placed to inform how best to provide palliative care in rural communities, an area where there has been little published work to date (5).

## PROGRESS IN PALLIATIVE CARE

In 2003, responsibility for the co-ordinator position, and other key elements of the service, became the sole responsibility of the local area health service. A key question for the original evaluation was the long-term sustainability of the project's model. In 2006, a re-evaluation of the service was initiated to identify the extent to which the needs of the local community were being met, whether improvements had been sustained and any further opportunities for service improvement.

### METHODS

Data were collected from a variety of sources, including a questionnaire sent to local GPs, interviews with key stakeholders, key documents such as minutes of the Board of Governance and de-identified patient level data from PalCIS. Patient registration details together with an initial phase are entered into the PalCIS clinical information system after referral to GAPS. Clinical data such as the Australian-modified version of the Karnofsky Index (6), the RUG-ADL (7) and the Problem Severity Index (8) are recorded in patients' home files which are returned to the Division of General Practice and entered into PalCIS when the patient dies.

The questionnaire was distributed to local GPs with a reply-paid envelope. The questionnaire sought data on time spent working as a GP in the local area, involvement in the GAPS programme, and opinions about the various elements of the model of service delivery – case conferences, patient-held records, admission rights to Griffith Base Hospital, use of standardised protocols, the after-hours service and education programmes.

Potential interviewees were approached to participate by the Murrumbidgee Division of General Practice (MDGP). Interviews were semi-structured with a list of questions to guide the interviewer. Notes taken during interviews were typed up and used as the basis for identifying themes. The evaluation was approved by the University of Wollongong/Illawarra Area Health Service Human Research Ethics Committee.

### RESULTS

Questionnaires were completed by five out of a total of 11 GPs, a response rate of 45%. Twenty-three people were

interviewed and three people were interviewed a second time to clarify points made during initial interviews and to check the factual accuracy of some information. One interview involved three people, one interview involved two people and the remaining interviews were conducted with individuals. Those interviewed included members of the GAPS Board of Governance, staff from the Division of General Practice, community nurses, health service managers, GPs, the GAPS co-ordinator and allied health staff.

### Governance

The GAPS Board of Governance was initially established to oversee performance, monitor quality and ensure fiscal accountability of the GAPS project. One of its key features was that it provided the project with a level of autonomy.

Five years later, the Board continues to meet monthly with a largely unchanged membership except for the addition of the general manager of the local area health service. GAPS is now funded by the local health service except for administrative support provided by the MDGP. Consequently, the MDGP has less control over GAPS and their involvement and influence with the programme has diminished. The Division has become frustrated with this and no longer sees itself as an active partner in GAPS.

There is tension between those who feel that GAPS should retain its own identity and degree of independence versus those who see the need to integrate GAPS with other services provided by the health service. There is general agreement that having strong community engagement at Board level was crucial to the success of the original project and should be maintained. However, involvement of community representatives has diminished over time.

### Utilisation of GAPS

Interviews with staff identified a degree of confusion about the GAPS referral criteria. Some stated that no referral criteria existed and comments were made that GAPS was best suited to those at the 'end-stage' of their disease and hence patients should not be referred 'too soon'. One trigger for referral is a clinical judgement that patients have reached the point where they would benefit from access to the 1800 on-call service.

Key indicators of service activity are summarised in Table 1. Since the original uptake and establishment of

**Table 1.** Indicators of service activity

Year	Referrals ( <i>n</i> )	In stable phase on referral (%)	Deaths ( <i>n</i> )	Dying at home (%)
2001 (last 3 months)	32	56.3%	12	50.0%
2002	60	70.0	41	45.0
2003	37	54.1	45	38.6
2004	47	66.0	44	34.1
2005	44	65.9	46	43.5
2006 (1st 3 months)	12	66.7	7	57.1%
Total	232	63.8	195	41.6

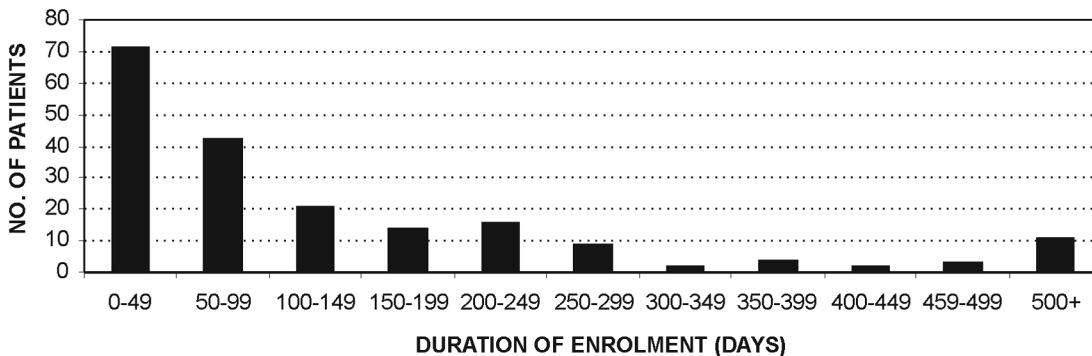


Fig. 1. Duration of enrolment of deceased patients, October 2001 to March 2006.

the programme in the last quarter of 2001, the number of referrals to GAPS has been relatively constant, averaging just over four per month. The majority of patients (63.8%) are in the stable phase at time of referral, with 22.8% in the unstable phase, 10.3% in the deteriorating phase and 1.7% in the terminal phase. Three patients were referred on the day of death for family bereavement management. There are some variations over time but, in general, the percentage in the stable phase has remained quite constant over the course of the programme. The two main sources of referrals are the oncology clinic at the local hospital (62.1%) and GPs (27.2%).

In total, 195 GAPS patients died between October 2001 and March 2006, for which the place of death is known for 190 patients. The percentage of patients dying at home has varied over the course of GAPS with an average of 41.6% (Table 1).

The one exception to this pattern was for approximately 8 months in 2004 when there was no GAPS co-ordinator. Although the number of referrals was stable, the percentage of GAPS patients dying in hospital during this time was higher than the time (before and after) when there was a GAPS co-ordinator (59.4% compared to 42.4%). This difference is not statistically significant ( $\chi^2 = 3.09$ ; 1 df;  $P = 0.08$ ).

**Primary diagnosis of enrolled patients**

There are a total of 110 different diagnoses for the 232 patients enrolled since the commencement of GAPS. The data indicate that there has been some success in extend-

ing GAPS to include patients with non-malignant disease, with an increase from 12.6% to 20.4% (Table 2).

**Duration of enrolment**

Figure 1 summarises duration of enrolment for the 195 GAPS patients that have died since the programme commenced. For 68.7% of patients, the duration of enrolment ranged from 0–149 days, with 5.6% of patients enrolled for more than 500 days.

The shortest duration of enrolment was zero days (three patients died on the day they were enrolled into the programme). The average duration of enrolment was 158 days with a median of 80 days. Although the data are not strictly comparable, the previous evaluation of GAPS produced similar results with a minimum duration of enrolment of 2 days and an average of 147 days.

The maximum duration of enrolment has increased considerably compared to the previous evaluation (from 509 days to 1515 days) and six patients were enrolled for more than 1000 days. In part, this is due to the fact that GAPS has been in operation for longer. The pattern of enrolment for current patients also shows long periods of enrolment with an average duration of enrolment of 569 days and 11 patients enrolled for more than 1000 days.

**Clinical assessment data**

The previous report on the evaluation of GAPS (2) included data on the number of phases, average time spent in each phase and distribution of the various clinical assessment tools by phase. Because of significant changes

Table 2. Patient diagnosis

Diagnosis	October 2001 to February 2003		March 2003 to March 2006	
	n	%	n	%
Cancer	78	82.1	104	75.9
Non-malignant	12	12.6	28	20.4
No diagnosis recorded	5	5.3	5	3.6
Total number of patients enrolled	95	100	137	100

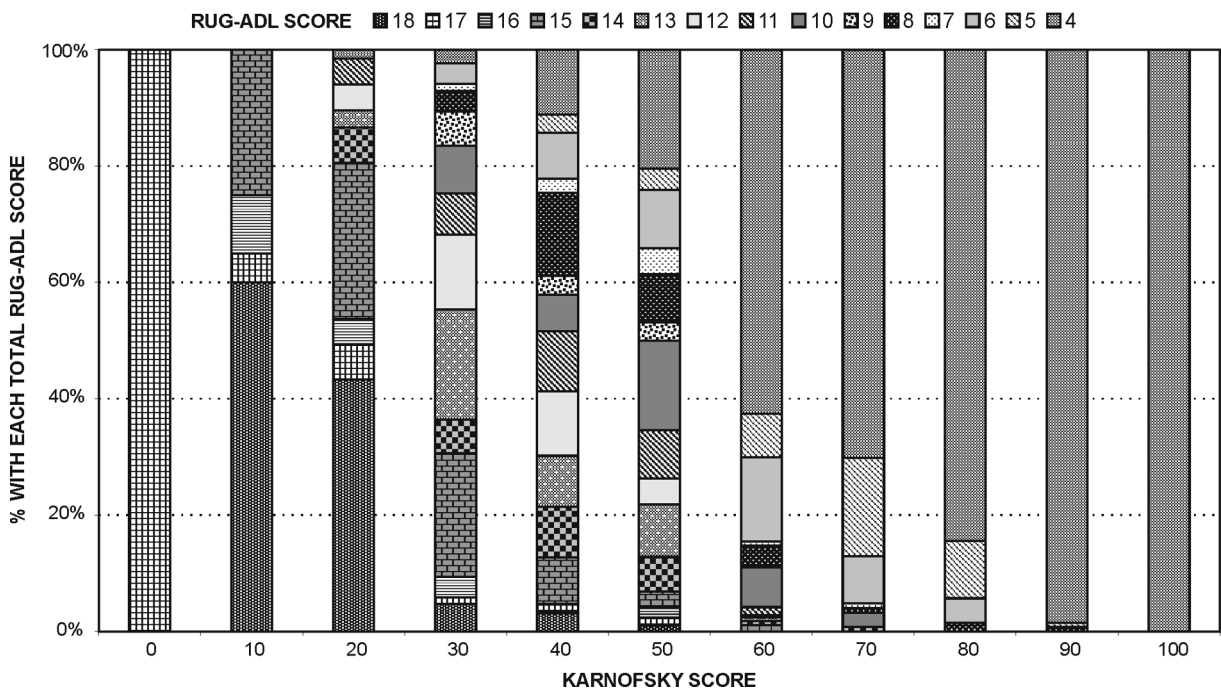


Fig. 2. Relationship between Karnofsky and total RUG-ADL scores.

in the collection and use of clinical assessment data since the initial 'project stage' of GAPS, this type of analysis is not repeated here.

However, we have explored the relationship between the Karnofsky Index score and the total RUG-ADL score for the 1211 instances where patients were assessed on the two instruments at the same time. The total score on the RUG-ADL ranges from 4 (highest level of independence) to 18 (lowest level of independence) and the Karnofsky Index ranges from 100 (normal with no complaints or evidence of disease) to 0 (death). There is an interesting relationship between these two assessment tools. Over one half of phases are scored in the middle range of the Karnofsky, where RUG-ADL provides a good discrimination between patients, as seen in Figure 2 and Table 3. 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 40 and 60. In contrast, the Karnofsky scale distinguishes between patients who are rated 4 on the RUG-ADL. This justifies the collection of both instruments.

**Admission to hospital**

A total of 271 hospital admissions were recorded for 123 patients, with 49.8% having a length of stay less than 4 days. Only a small number of patients stayed in hospital for more than 2 weeks. On average, patients enrolled in GAPS have been admitted to hospital twice, with a minimum and maximum number of admissions of 1 and 17, respectively. The majority of patients (56.5%) were in the

unstable phase at their last recording of phase prior to hospital admission and 28.4% in the stable phase.

**Case conferences**

Case conferences occur weekly and have become part of the day-to-day practice of those who participate. There has been a decline in GP attendance, with 4 or 5 GPs attending the meetings early in the life of GAPS whereas current attendance is largely restricted to two GPs. Only a very small number of Enhanced Primary Care items are claimed following the meetings to recompense GPs for their attendance (approximately five per year).

In general, there is strong support for the meetings with comments such as 'an excellent part of the project', 'an excellent initiative' and 'offers good support for GPs and very positive to tie in with community nursing'. All three GPs who responded to questions about case conferences in the GP Questionnaire agreed that the case conferences improved co-ordination of services, communication with non-clinical aspects of care and sharing of ideas about palliative care.

The meetings have a strong emphasis on communication, particularly to ensure that those involved in the after-hours, on-call nursing roster are well informed about current patients. However, developing formal care plans is not a feature of the meetings and there is no formal documentation of decisions that are made.

**Shared service protocols**

Protocols for the GAPS programme were developed during the original project but have not been updated since

**Table 3.** Relationship between Karnofsky and total RUG-ADL scores

RUG-ADL	Karnofsky score											Total (n)	Total (%)
	0	10	20	30	40	50	60	70	80	90	100		
4			1	2	14	45	182	87	119	131	3	584	48
5					4	8	22	21	14	1		70	6
6				3	10	22	42	10	6			93	8
7				1	3	10	2	1				17	1
8				3	18	18	10	1	2	1		53	4
9				5	4	7	1					17	1
10				7	8	34	20	3				72	6
11			3	6	13	18	4					44	4
12			3	11	14	10	1					39	3
13			2	16	11	20	2					51	4
14			4	5	11	13	2	1				36	3
15		5	18	18	10	6	3					60	5
16		2	3	3		4						12	1
17	1	1	4	1	2	3						12	1
18		12	29	4	4	2						51	4
Total (n)	1	20	67	85	126	220	291	124	141	133	3	1211	100
Total (%)	0	2	6	7	10	18	24	10	12	11	0	100	

then. There is no evidence that the document is referred to on a regular basis and some clinicians were unaware of its existence. Some clinicians were of the view that because they knew the procedures so well, there was no need to refer to written protocols.

**Access line**

The after-hours, call-out service involves a 1–800 number that patients or carers can use to contact GAPS. The calls are logged and about half of all calls generate a call-out visit (Table 4). The call-outs for the years 2001 and 2002 do not specify whether a nurse or a doctor visited the patients. Of the 273 call-outs from 2003 to 2006, all were attended by a nurse and 12% (n = 32) involved a doctor also visiting the patient.

The availability of the after-hours service is generally recognised as a key component of the GAPS service. GPs particularly like having a nurse on-call to act as the first response to any calls. Four out of five GPs completing the GP Questionnaire agreed that provision of the after-hours service improved co-ordination of the clinical service (one

GP responded that it did not improve co-ordination). The same four GPs agreed that the after-hours service improved communication between those involved in providing care after hours. Comments about the after-hours service made during interviews included:

- *‘the on-call roster works well because the doctors place so much trust in the nurses’*
- *‘the on-call service is the main advantage of the GAPS programme’*
- *‘this part of the service works well’.*

Three issues of concern were identified during interviews with staff: (i) being on-call can be onerous during periods when only a small number of staff are included in the roster; (ii) community nurses no longer participate in the on-call roster; and (iii) the on-call roster is very expensive.

**Direct admission to the ward**

There is a written procedure to allow for direct admission to a ward bed for patients registered with the GAPS programme, thus avoiding the need to attend the emergency department. This is generally viewed as a very positive aspect of the GAPS programme as it avoids the need for palliative care patients to spend long periods of time waiting unnecessarily in the emergency department. Staff in the emergency department have a list of GAPS patients and will direct any patients presenting unexpectedly to the emergency department to a ward bed. The only concern expressed about this practice was that this may result in some unnecessary admissions to hospital. Review by a doctor in the emergency department (if it were to occur)

**Table 4.** After-hours call-outs

Year	Calls (n)	Call-outs (n)	Call-outs (%)
2001 (last 3 months)	3	3	100
2002	100	49	49.0
2003	127	65	51.2
2004	160	83	51.9
2005	184	99	53.8
2006 (first 3 months)	50	26	52.0
Total	624	325	52.1

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might result in a small number of patients being discharged home, rather than admitted to hospital.

### Patient-held record

The patient-held record is a feature of the GAPS programme that worked well during the first 18 months of the programme. Although we did not seek the opinion of patients about patient-held records stakeholder interviews indicated that the records remain important. All five GPs responding to the GP survey confirmed that they entered information in the patient-held record either 'usually' or 'sometimes'. All reported that the information in the patient-held record was either 'accurate' or 'moderately accurate' and that they rated the patient-held record as useful. This feedback was consistent with views expressed during interviews, which also indicated that the records are of more value to clinicians than they are to the patients themselves.

The records are used to record, diligently, the phase of palliative care, problem severity scores, RUG-ADL scores and Karnofsky scores. However, as with any dedicated record system, issues can arise from lack of integration with existing systems and this came out during our interviews with comments that the patient-held records resulted in some 'doubling up' of record keeping.

### Organisation of care delivery

During the first 3 years of GAPS, the co-ordinator role was largely one of co-ordination, with no 'hands on' clinical role. Since late 2004 there has been a significant change with the co-ordinator (a nursing position) taking clinical responsibility for GAPS patients, with less involvement of community nurses. The GAPS co-ordinator now provides the majority of 'in-hours' nursing care. The net result is that GAPS has moved from being a primary care team model of practice to a 'quasi-specialist' service where the bulk of nursing care is delivered by a nurse specialising in palliative care. The after-hours, on-call nursing roster also reflects this situation with community nurses not included in the roster. There was a general consensus amongst those we interviewed that the co-ordinator role is 'too clinical' and that there should be a better balance between clinical and non-clinical responsibilities.

### Data management

The current practice of entering data retrospectively into PaICIS after death means that there is no incentive to use the information to inform practice and/or service planning. However, the data are used to run a report for the weekly multidisciplinary meeting and monthly Board of Governance meeting.

The previous evaluation report identified that clinical items such as phase were being used by clinicians as a 'real time' common language. Phase is still being used at the

weekly case conferences to identify a patient's stage of illness but none of the other clinical assessment data is being used as part of day-to-day communication between clinicians.

## DISCUSSION

A clear impression from interviewing stakeholders is that the very use of a simple acronym such as GAPS has greatly assisted a sense of identification with, and local ownership of, the programme. The term GAPS is well understood by health professionals, patients and the community alike. However, some tensions have emerged between having a separate programme and incorporating palliative care into mainstream service delivery. This tension manifests itself in two main ways – in the governance arrangements and the organisation of nursing care – with each, to a degree, pulling in opposite directions. Governance is now largely the responsibility of the local health service whereas nursing care has moved from a generalist to a specialist model. This represents a good example of the issues that can arise when a project is used as the vehicle to implement change but those who end up with on-going responsibility for managing the change have a different view (and role) to those initiating the change.

There is a palpable sense of loss by the Division of General Practice that 'their project' has, in a sense, grown up and left home. Conversely, the local area health service now sees GAPS as one of 'their services' with the responsibilities for on-going funding and organisation that comes with that. Community nurses have disengaged from GAPS with the move to a service that relies heavily on the work of one person, the GAPS co-ordinator, for the provision of nursing care. Both factors indicate the need for a stronger sense of direction for GAPS, including a clear decision about the preferred model of care, primarily the organisation of nursing care. The most appropriate framework for providing such direction is now available in the form of national policy documents for service planning, (9) service development (10) and setting standards (11).

One of the aims of GAPS has been to extend the service beyond caring for patients with cancer. There is some indication that more people with non-malignant conditions have been referred to GAPS in the last 3 years than during the original 'project phase' of GAPS. However, there is some potential confusion regarding the referral criteria for GAPS.

Despite month-to-month variations, the number of referrals per month, the percentage of patients in the stable phase on referral and the percentage of patients dying at home have remained relatively constant over the course of the programme. This suggests a relatively stable pattern of service delivery. Patients do not appear to be referred to GAPS later in their disease process (which would result in



the percentage of patients in the stable phase on referral decreasing over time). This observation is tempered by the fact that most patients spend long periods of time in the stable phase, so a significant change in referral practice would be required to change the number of patients in the stable phase at time of referral.

## CONCLUSIONS

The previous evaluation identified the four elements of the GAPS model that worked most effectively, namely: (i) weekly case conferences; (ii) 1–800 number and on-call nursing roster; (iii) patient-held record; and (iv) shared protocols and procedures.

This has now been reduced to two – the weekly case conferences and the on-call arrangements. Both have become part of day-to-day practice, achieving an excellent level of sustainability. The two complement each other, particularly in the way the case conferences are used to facilitate communication about patient information between those involved in the on-call roster. The on-call nursing roster works well but is expensive. The number of calls and the number of call-outs have been steadily increasing.

GPs have continued to support and be involved in GAPS, although there are some concerns that involvement in case conferencing has declined since the programme began. Together with the good working relationship between GPs and other clinical staff and maintenance of the co-ordinator position, these factors provide the important ‘glue’ that keeps the programme together.

The use of clinical assessment information (a key feature of the original GAPS project) has changed to the point where data are no longer used as a ‘real time’ common language amongst clinicians. The retrospective nature of most of the data entry into PalCIS reduces the ability to use the data to gauge effectively how the service is changing or progressing. The use of common clinical assessment tools is being tested as part of the national Rural Palliative Care Program and the results from that programme will inform providers wanting to use such tools in their everyday practice. The experience from GAPS suggests that use of common clinical assessment tools can be sustained but the important question is not ‘can these data be collected?’ but ‘how can these data be used?’

The previous evaluation in 2003 identified noticeable improvements to service delivery, some of which have been maintained. However, several key features have not been maintained or have changed, with the most significant being the disengagement of community nurses from the programme and a move to a more specialised nursing service.

## ACKNOWLEDGEMENTS

This study was commissioned by the Murrumbidgee Division of General Practice with funding from the Commonwealth Department of Health and Ageing and approved by the University of Wollongong HREC.

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