

**National Standards Assessment Program**  
Improving quality in palliative care



**NSAP Continuous Quality Improvement Collaborative Projects:**

# **Support for Carers**

**Evaluation Report 2014**

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## Executive Summary

The National Standards Assessment Program (NSAP) is a quality improvement program available to all specialist palliative care services across Australia. NSAP facilitates services to engage in continuous quality improvement through self-assessment against national palliative care standards, action plan development and implementation, as well as peer mentorship (Palliative Care Australia, 2005). In 2011 NSAP identified four national priorities for improvement in specialist palliative care services, based on analysis of the self-assessment results submitted by 108 services up to June 2010, which included 1909 items for review. The priorities were:

- 1) skill development in continuous quality improvement;
- 2) assessment and care planning;
- 3) support for carers;
- 4) education provision (National Standards Assessment Program, 2011).

In response to the first two priorities NSAP initiated and funded the National Standards Assessment Program Collaborative Improvement: Assessment and Care Planning Project (NSAP CIP: ACP). The purpose of this first national project, commenced in 2011, was to address the assessment and care planning for palliative care patients and to enhance staff skills in continuous quality improvement. The project aimed to provide a patient centred and holistic assessment and holistic care planning which demonstrated patient involvement. The findings and recommendations from this project are reported elsewhere (Palliative Care Australia, 2012); the reported improvements in delivery of care across 20 specialist palliative care services prompted the conduct of a second similar national project to improve support for carers of palliative care patients.

As a result in 2013, NSAP commissioned the *Continuous Quality Improvement Collaborative Project: Support for Carers* to further address identified priority areas. The focus of this project was the continued enhancement of skill development in continuous quality improvement and the development of better support processes for carers of palliative care patients. Forty specialist palliative care services from across Australia volunteered to participate, ten of which also took part in the first collaborative improvement project. NSAP identified the objective of this second project as the improvement of assessment, planning and delivery of support in meeting the needs of carers of palliative care patients. This objective is directly aligned to Standard 5 of the national palliative care standards for providing quality palliative care for all Australians: “The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes” (Palliative Care Australia, 2005). In order to achieve the project objective, NSAP identified three aims:

1. All patients will have identified a carer
2. All carers will have discussed the caring role with a health professional and agreed to be the patient’s carer
3. All carers will have a needs assessment completed and a documented plan of action.

These aims were in reference to the “Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients” (Hudson et al., 2010a).

NSAP managed the project, which adopted the Institute for Healthcare Improvement Breakthrough Series collaborative model to help participating specialist palliative care services improve their

performance (Institute of Health Care Improvement, 2003). Each participant implemented the Plan, Do, Study, Act (PDSA) model to review and improve their systems and processes for assessment, planning and delivery of support for carer. Participating services addressed different areas of care related to the “carer”; a collaborative approach ensured that a wide range of settings and solutions were trialled. The “Clinical Practice Guidelines for the Psychological and Bereavement Support of Family Caregivers of Palliative Care Patients” published by Hudson et al in 2010 was primary resource.

NSAP commissioned an evaluation of this project in order to understand and improve national practices regarding the role, assessment and planning of care for carers of palliative care patients. The summative project evaluation sought to evaluate generic process outcomes across participating services and to report on the group achievements related to the projects that specialist palliative care services undertook. Consultation with the project Expert Reference Panel resulted in a descriptive, quantitative evaluation design (Appendix 1). The project used medical record audits from participating services to collect data on assessment and care planning for carers of palliative care patients, which were analysed as the primary data source in the evaluation. The evaluation questions and performance measures were directly informed by the “*Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients*” (Hudson et al, 2010a). The project aims, evaluation questions and guideline references are summarised in Appendix 2. The agreed evaluation questions and quantitative performance measures used in the project were:

**Does the patient’s record evidence that the patient has identified a carer(s) and the carer(s)’ role?**

Performance measure: Percentage of patient records with evidence that the patient has identified their carer(s).

Performance measure: Percentage of patient records with evidence that the patient has identified the carer(s)’ role.

**Does the patient’s record evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role?**

Performance measure: Percentage of patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role.

**Does the patient’s record evidence that the carer is aware of palliative care and other services and resources that are available to support their role?**

Performance measure: Percentage of patient records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role.

**Does the patient’s record evidence an assessment of the carer(s)’ needs?**

Performance measure: Percentage of patient records with evidence of an assessment of the carer(s)’ needs.

**Does the patient’s record evidence a documented plan of action to support the carer(s)’ needs?**

Performance measure: Percentage of patient records with evidence of a documented plan of action to support the carer(s)’ needs.

The strong commitment of participating service staff to the collection and submission of data on the performance measures was an important factor in the evaluation. Analysis of the data from participating services showed overall improvement for each performance measure. The analysis does not include individual service project data, a responsibility that fell to individual organisations. A review of the project's collaborative improvement model, project administration and assessment of quality initiatives was outside the scope of this evaluation. The quantitative performance measure results are detailed in the following report.

While the project results have evidenced improvement, there is continued opportunity to improve the service delivery processes that support carers. Recommendations for further evaluation follow:

- The validity of the quantitative measures needs to be extensively researched before they can be reliably used in the wider palliative care setting.
- Inter-rater reliability of performance data in individual services needs to be completed in future projects.
- The identification of factors that potentially impact data variability needs to be explored in the design of performance measures.
- The need for consideration of specific work areas for individual projects as this impacts the scope of the final analysis.
- The need to consider the use of specific audit tools in the project, which would ensure consistent data collection across all projects.
- The process measures used in this evaluation do not measure "carer outcomes". Measuring these could provide a different perspective on health care service delivery.
- A mixed methods design using qualitative and quantitative methods would provide greater insight into how care is delivered for carers. For example, the percentage of patient records with evidence of an assessment of the carer(s)' needs provides a result but the construct of "the assessment" and why the results were low is not answered.
- Ideally, a quality improvement program should identify and address the concerns of all stakeholder groups involved in the area of care. In this project the health service provider perspective dominated; ongoing improvement in individual service projects should broaden the stakeholder scope.

In summary, it can be concluded that the project was successful. Anecdotally, participation enhanced participants' skills, knowledge and confidence in the use of quality improvement techniques. Participants reviewed and improved practices in assessment and planning for carers using the PDSA improvement model. Performance data identified weaker performing areas in the assessment and planning of care, resulting in subsequent practice improvements. This project supports the continuation of the collaborative improvement model as the preferred approach for future improvement in palliative care services. The following report presents the approved evaluation approach and its results.

***"NSAP thanks project participants for completing monthly data surveys which informed this evaluation."***

## Evaluation Approach

A quantitative descriptive design was used to explore and describe the project evaluation questions.

**Evaluation questions:** The following five project evaluation questions were agreed upon by the project Expert Reference Panel (Appendix 1) in order to explore the “carer” construct in caring for a palliative care patient:

- 1 Does the patient’s record evidence that the patient has identified a carer(s) and the carer(s) role?
- 2 Does the patient’s record evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role?
- 3 Does the patient’s record evidence that the carer is aware of palliative care and other services and resources that are available to support their role?
- 4 Does the patient’s record evidence an assessment of the carer(s)’ needs?
- 5 Does the patient’s record evidence a documented plan of action to support the carer(s)’ needs?

Each evaluation question was aligned with a specific project aim and related to the Clinical Practice Guidelines for the Psychological and Bereavement Support of Family Caregivers of Palliative Care Patients (Hudson et al., 2010a). A summary of the evaluation questions, project aims and guidelines reference are included in Appendix 2.

**Performance measures:** A review of the literature to identify tools/instruments to evaluate care processes related to supporting family caregivers of palliative care patients identified several instruments; however no specific advice was provided on generic performance measures that could be used for a collaborative improvement project (Hudson et al., 2010b). The performance measures were developed in consultation with the project Expert Reference Panel (Appendix 1). Relevant definitions are included in Appendix 3. The agreed performance measures for the Carer Support Project include:

1. Percentage of patient records with evidence that the patient has identified their carer(s) (P1A).
2. Percentage of patient records with evidence that the patient has identified the carer’s role (P1B).
3. Percentage of patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role (P2).
4. Percentage of patient records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role (P3).
5. Percentage of patient records with evidence of an assessment of the carer(s)’ needs (P4). Eight audit criteria to be evidenced in the audit of the carer(s)’ needs were: physical, psychological, social, cultural, financial, death preparation bereavement needs and spiritual assessments.
6. Percentage of patient records with evidence of a documented plan of action to support the carer(s)’ needs (P5).

Specific details for each performance measure are included in Appendix 4.

## Evaluation method

**Setting:** The project setting is specialist palliative care services in Australia. These services include direct care (inpatient), ambulatory (community) and consultative services. Various models of care delivery are used across the specialist palliative care services. Each participating service nominated a specific project focus; for example, one particular specialist palliative care service may include consultative, ambulatory and direct care service delivery but for the project purposes the service may have nominated to focus on ambulatory services only. All participating services were involved in the National Standards Assessment Program and all completed a formal agreement with NSAP to take part.

**Sample:** A convenience sample of medical records for palliative care patients attending the participating specialist palliative care services was audited in each service to collect the performance data. Each participating service was requested to submit audit data for the last 20 patients admitted to their service in the current month (a census was requested if fewer than 20 patients were admitted within the month).

**Data collection:** The evaluation used a medical record audit to collect and analyse data relevant to the assessment and care planning for carers of palliative care patients. NSAP collected the audit data using a survey approach supported by SurveyMonkey web based software. De-identified monthly data sets were provided to the evaluator in an excel spreadsheet.

The project data were collected monthly from May 2013 (baseline data) until March 2014 (project completion). The May 2013 data set was collected to provide baseline project data before formal project work began (no PDSA cycles had been commenced).

**Data analysis:** Monthly data sets were analysed using descriptive statistics including trends in performance and summary graphical displays. This analysis does not include individual service project data; this was the responsibility of individual services.

The statistics completed for each performance measure (rounded to the nearest whole number) are:

- Percentages across the projects; these are relative to the specific audit percentage results completed by individual projects. Specific measures include the average, Q1, median, Q3, minimum and maximum.
- Percentages split by project focus for both direct care (inpatient) projects and ambulatory (community) projects.

*Group comparisons are not included for the consultative project focus or mixed projects. These groupings are not shown because the limited number of projects in these groups potentially identifies the services. Similarly, Australian States and Territories were not compared because of the limited number of projects.*

- The project goal for each performance measure was 80%. The project goal for the percentage of services achieving the performance measure goal was also 80%.

A common graphical format is used to display the results for the performance measures. The following diagram describes the conventions used in this display.

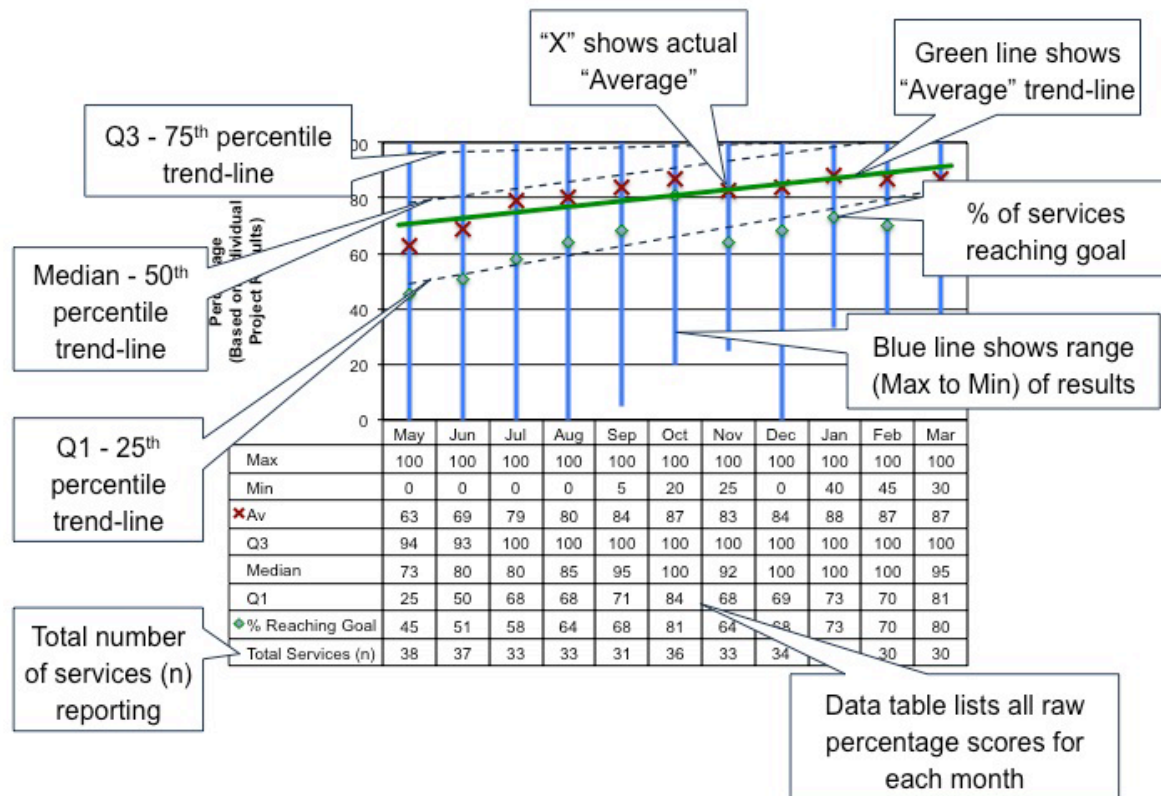


Figure 1: Notes on the common format

**Reliability and validity of performance measures data:** The reliability and validity of the data limit the evaluation. The data were collected from several different services and the scope of the project did not allow for completion of any inter-rater reliability analysis. The performance measures were developed specifically for this project as no validated measures could be obtained from the initial literature review. An expert reference panel reviewed only the validity of the content of these measures prior to project commencement. The practicality of the measurement process considers the time to collect data, number of data items being collected, utility of data collection templates and the participants’ understanding of what is being measured. An open-ended question was included in the monthly survey to collect data to explore potential practicality issues.



## Findings

### Project data

The number of services that submitted data over the May 2013–March 2014 period varied. Of the 40 services initially enrolled in the project one service did not undertake it. Discussion of the administrative reasons for services not continuing in the project and or not submitting monthly data are not within the scope of this report. The anonymous data sets participating services submitted were reviewed prior to inclusion into a monthly group data set. Following the review of the monthly surveys some were deleted for the following reasons: 1) no data were included in the survey, 2) errors in the data. Service data sets used in the group evaluation each month varied between 30 and 38 services. A summary of the monthly data sets used is shown in Table 1 below.

Audit month	Services enrolled	Data sets submitted	Data sets used	% of enrolled services' data sets used
May 2013	39	38	38	97%
June 2013	39	38	37	95%
July 2013	38	35	33	87%
Aug 2013	37	35	33	89%
Sept 2013	37	33	31	84%
Oct 2013	37	36	36	97%
Nov 2013	37	35	33	89%
Dec 2013	37	34	34	92%
Jan 2014	37	33	33	89%
Feb 2014	35	32	30	86%
Mar 2014	35	32	30	86%

Table 1: Summary of project data sets

Organisations nominated specific service areas for their project and improvement PDSA cycles; the majority of projects focused either on direct (inpatient) care or ambulatory (community) contexts. A minority of services nominated consultative care and some a mixed project focus (e.g. direct and community).

## Number of audits completed

The number of audits completed each month shows a downward trend. This may have been due to a decrease in the number of services submitting data, with some data not included for reasons discussed above. Figure 2 summarises monthly audit numbers.

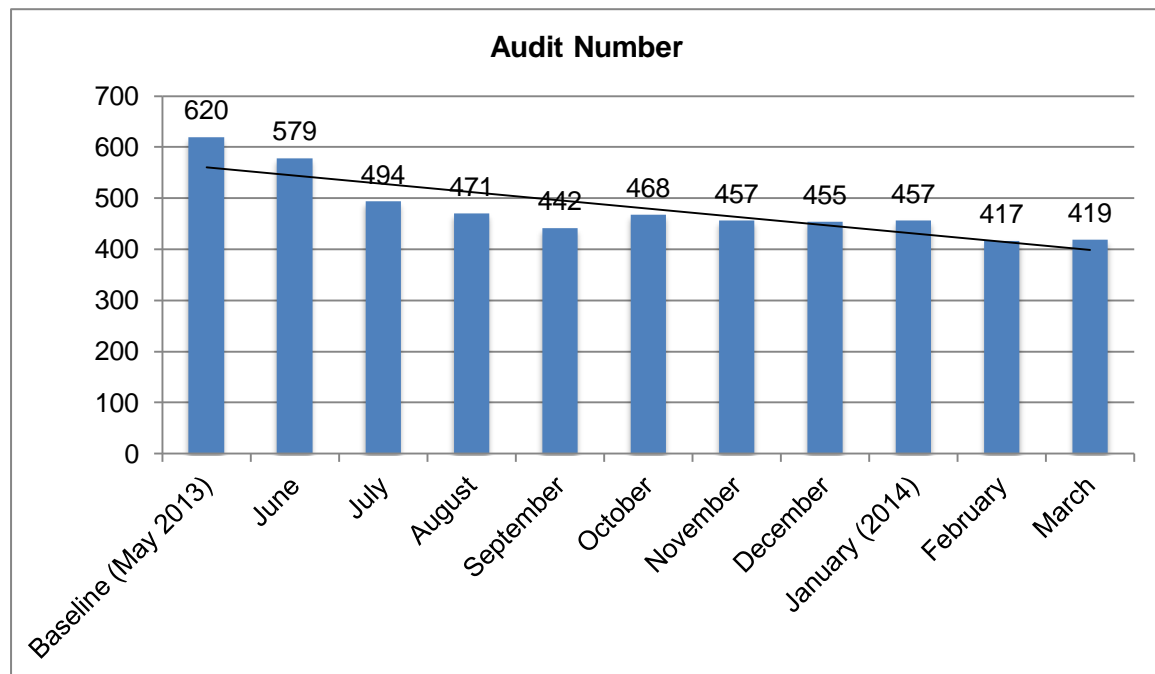


Figure 2: Monthly audit number across the project

## Performance measure practicality

Evaluation and performance measures were extensively discussed and initial queries addressed in the first collaborative learning session (June 2013). Consensus across participants at the first workshop resulted in redefining of the first performance measure (percentage of patient records with evidence that the patient had identified their carer(s) and the carer(s)' role) into two measures:

- Percentage of patient records with evidence that the patient has identified their carer(s) (P1A).
- Percentage of patient records with evidence that the patient has identified the carer(s)' role (P1B).

Following this initial amendment the monthly survey requested qualitative comments about the practicality of the performance measures. Teleconferences were scheduled with all participants as needed to discuss performance measure issues.

NSAP convened the first teleconference in August 2013 to discuss comments and issues on performance measures submitted in the May 2013-June 2013 surveys. These included:

- *Difficulty finding information about carers.*
- *Identified place for carer information not completed or filled with same information as contact person.*

- *A number of patients surveyed stated that they neither had nor required a carer – this is hard to report in this project.*
- *Our service is using a patient electronic record system and it is challenging to get the data as we are unable to look at all completed assessments.*
- *What happens if [a] client has dementia and cannot identify a carer?*
- *What is meant by 'physical' e.g. - physical health of the carer and their needs, or the physical ability of the carer to provide physical care...*
- *What if the carer does not have needs within the needs assessment process? We assume carers need support – what if they are doing really well?*

Specific issues addressed in the first teleconference related to 1) number of audits, 2) no carer, 3) inability to identify a carer, and 4) accessing information.

It was agreed from the July 2013 audit period to include a survey question that identified the number of records audited that stipulated “no carer”; these records were not to be included in the monthly analysis. The relevance of this data was to flag that not all palliative care patients had a carer. This may have been because they chose not to – or alternatively – there was no one who could accept responsibility for the role. This topic generated several conversations indicating that this was an important area for further investigation.

NSAP convened a second teleconference in November 2013 (three alternative times were scheduled to provide flexibility for service participation) giving participants an ongoing opportunity to discuss project evaluation. Seven themes emerged with the emphasis on collecting, presenting and using data. Most questions/areas for discussion that project participants presented were not specific to performance measures criteria but focused on general evaluation questions. The themes discussed are summarised below:

#### Theme 1: Sampling

- *How do we discuss/explain sample size?*
- *How do we discuss impact of sample size when presenting individual and/or national data?*
- *Can we discuss changing the audit sample if looking at continuing data collection?*

#### Theme 2: Data collection

- *Data collection is a nightmare! Please discuss.*
- *Usually one person collected the data but when they were away someone else audited the charts and came up with very different results – why is this?*
- *Can we discuss data checking / cleaning – 'how to'?*

#### Theme 3: Post project data collection

- *Please discuss continuing data collection post-project – e.g. how often is it needed/recommended?*
- *How could we make data collection easier and therefore more sustainable?*
- *Please can we discuss any examples of electronic systems for data collection being used?*

#### Theme 4: Data presentation

- *How can data be used to present a business case for additional resources?*
- *Is there a 'Script' for confidently presenting data e.g. analysis, limitations?*
- *How do you present/speak to comparisons of individual data with group data?*
- *How do we present and speak to our service's individual data?*

#### Theme 5: Using the data

- *How is weak data explained?*
- *How can we use data to emphasise the importance of documentation?*
- *In order to benchmark like-with-like - is it possible to look at group data by state or by inpatient vs. community settings?*
- *How do we engage the rest of the team in a meaningful way to review and analyse data?*

#### Theme 6: Process versus outcome data

- *How could we look at measuring the impact of this project on carers?*
- *Are there other indicators routinely collected already by services that could measure/reflect improved carer support, e.g. rates of deaths at home, rates of re-admission, PCOC indicators?*
- *Please can we discuss what other concurrent initiatives (e.g. other quality projects) that may have contributed to improvements in our data?*

#### Theme 7: Dissemination of results

- *How can we share and discuss definitions/criteria of the indicators for audit purposes (e.g. assessment of cultural and spiritual needs)?*

The November 2013 teleconference encouraged open discussion about the evaluation. However, participants offered limited comment on actual performance measures.

In the final March 2014 survey, project participants were encouraged to comment on the evaluation, particularly the performance measures. The importance of their opinions about the performance measures and evaluation strategy had been emphasised in the November teleconferences; they could provide valuable advice for future initiatives in supporting assessment and planning for carers of palliative care patients. Appendix 4 elucidates participants' overall opinions of the evaluation.

## Performance measures

A summary of the key findings by question and performance measure is shown below.

### Question 1: Do palliative care assessments evidence that the patient has identified a carer(s) and the carer(s)' role?

#### Performance Measure 1A (P1A)

Percentage of patient records with evidence that the patient has identified their carer(s).

These data are calculated using the individual project results (project audit result/project audit number \* 100). This performance measure showed an upward trend improving from 63% at the baseline and achieving the project goal (80%) in August 2013. A summary of the data is shown in Figure 3 below.

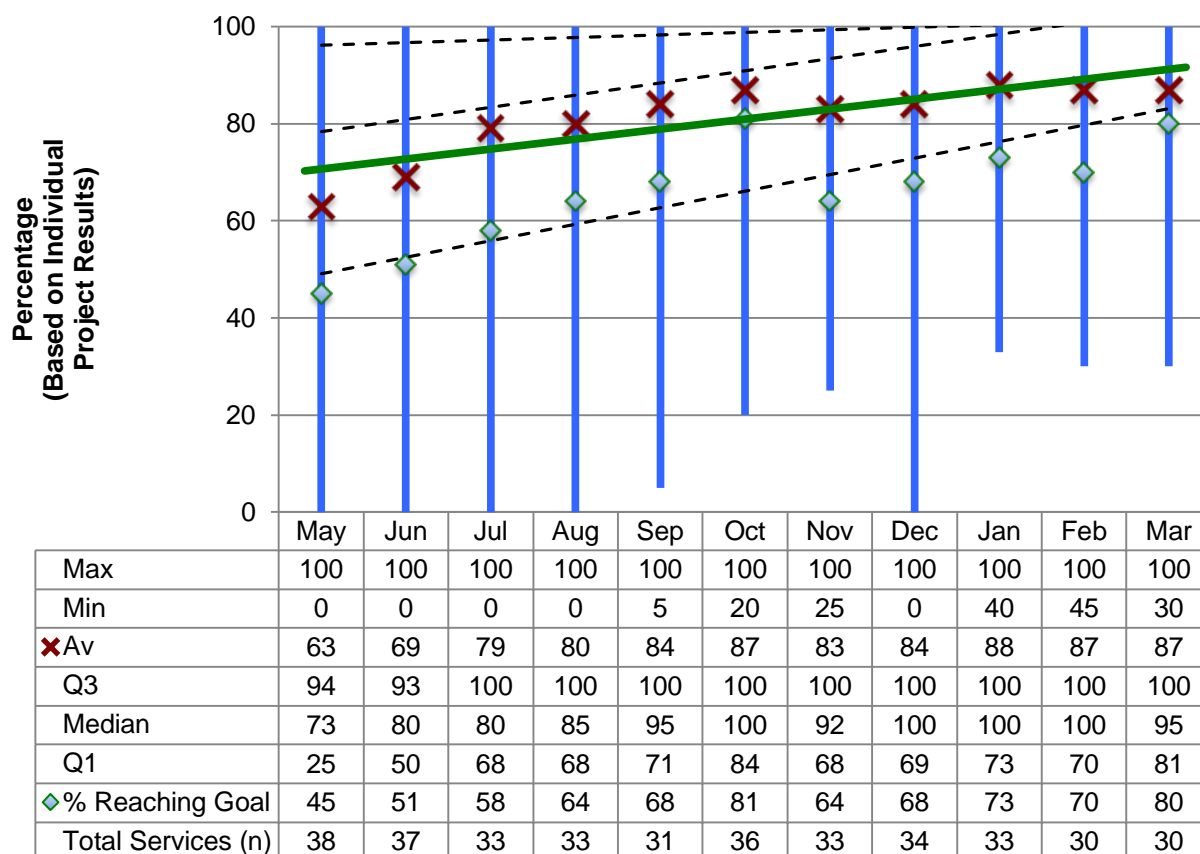


Figure 3: Percentage of patient records with evidence that the patient has identified their carer(s).

The results for this measure show that the percentage of patient records with evidence that the patient has identified their carer(s) improved from the start of the PDSA project cycles in June 2013. Analysis of the group project data for P1A supports the following conclusions:

- Initially the best reported performance measure from project outset, all measures (Q1, median, Q3 and average) of P1A improved over the duration of the project.

- The individual project average for P1A improved from 63% to 87% during the project and is the only measure that exceeded the Project goal of 80%. This supports that the patient identified their carer(s) in the majority of records audited.
- Nearly half of all services achieved the project goal from the outset.
- 80% of services reached or exceeded the project goal.
- While nearly half of all services achieved a 100% return, there remained a large range (70%) between services.
- While some services struggled with this performance measure at project completion, there was still strong improvement in the lower quartile throughout the project.

**Percentages split by project focus for: 1) direct care projects and 2) ambulatory projects**

Figure 4 summarises the average percentage of patient records with evidence that the patient had identified their carer(s) by project focus. The ambulatory (community) projects performed slightly higher than direct care (inpatient) projects in this measure. No statistical significance is considered for this comparison because the care processes underpinning the performance measure are not confirmed. The ambulatory (community) projects reached the project goal of 80% by August 2013 and continued to improve for the remainder of the project. In contrast the direct care services achieved the project goal of 80% in October 2013, however this was not sustained over the remainder of the project. By March 2014, although close to the project goal, the direct care services averaged 78% on this performance measure.

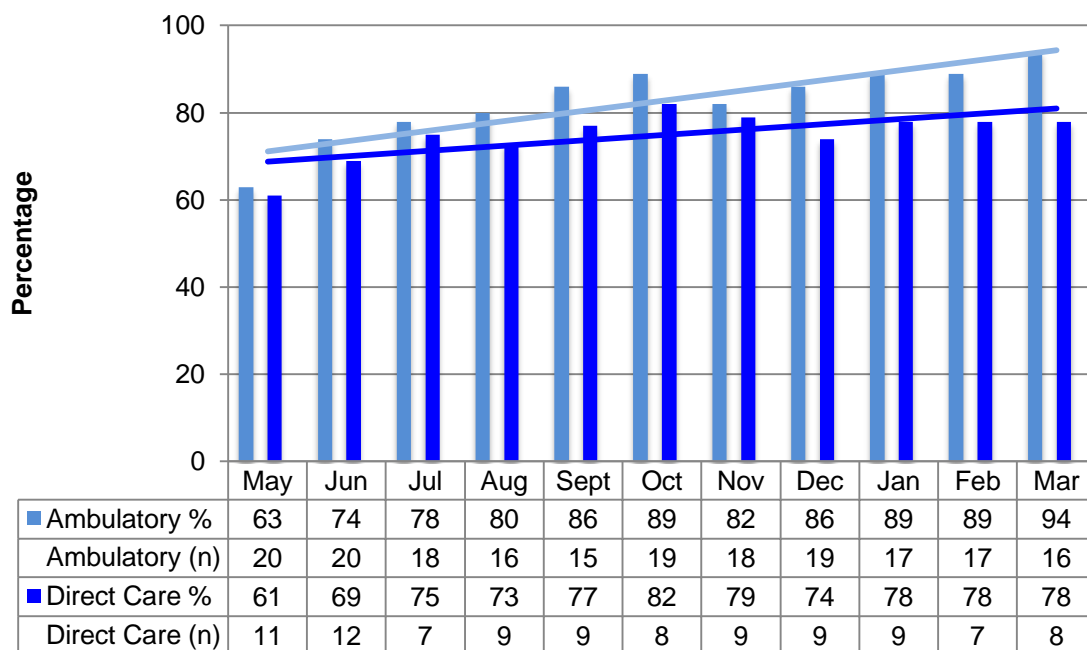


Figure 4: Average percentage of patient records with evidence that the patient has identified their carer(s) by project focus.

### Performance Measure 1B (P1B)

Percentage of patient records with evidence that the patient has identified the carer(s)' role (P1B).

These data are calculated using the individual project results (project audit result/project audit number \* 100). This performance measure showed an upward trend improving from 42% at the baseline and achieving 73% in March 2014. The data is summarised in Figure 5 below.

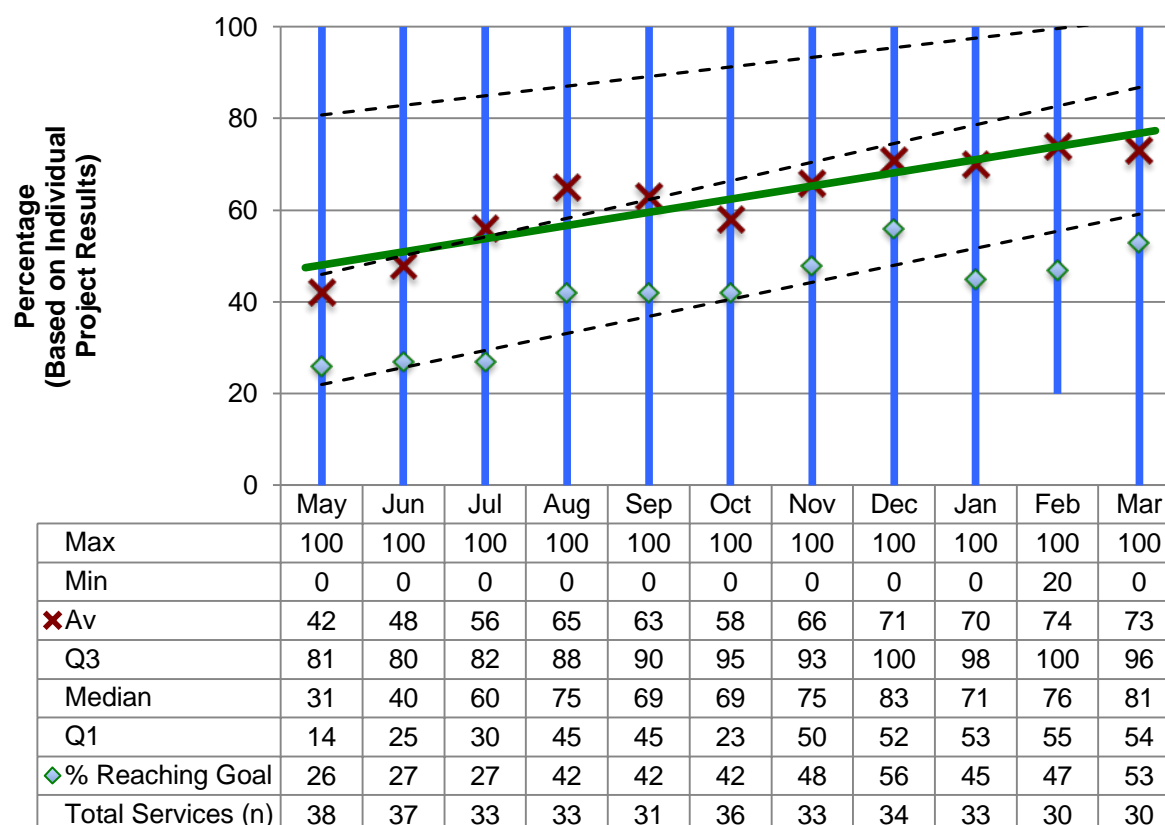


Figure 5: Percentage of patient records with evidence that the patient has identified the carer(s)' role.

The results for this measure confirm that the percentage of patient records with evidence that the patient had identified the carer(s)' role improved through the PDSA project cycles in June 2013.

Analysis of the group project data for P1B supports the following conclusions:

- All measures of P1B (Q1, median, Q3 and average) showed an upward trend throughout the project until December and then seemed to plateau for the remainder of the project.
- The individual project average for P1B improved from 42% to 73% during the project but did not reach the project goal of 80%.
- Just over one in four services achieved project goal from the outset.
- More than half the services achieved the project goal.
- While just less than one quarter of services achieved a 100% return, there remained a large range (100%) between services.
- While some services continued to struggle with this performance measure towards project completion, there was still strong improvement in the lower quartile and median throughout.

**Percentages split by project focus for: 1) direct care projects and 2) ambulatory projects**

Figure 6 summarises the average percentage of patient records with evidence that the patient has identified the carer(s) role by project focus. Both the direct care (inpatient) and ambulatory (community) projects showed a steady increase in this performance measure. The ambulatory group reached 76% in February and March 2014. The direct care projects showed steady improvement reaching 74% at the end of the project. Neither group achieved the project goal of 80%.

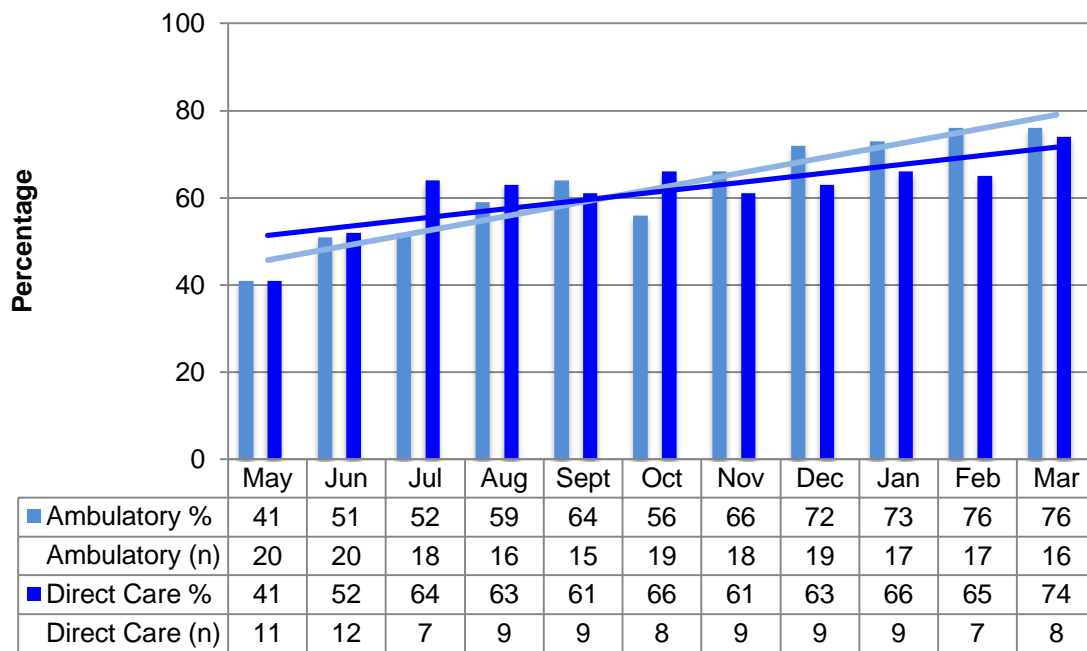


Figure 6: Average percentage of patient records with evidence that the patient has identified the carer(s) role by project focus.



**Question 2: Does the patient’s record evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role?**

**Performance Measure P2 (P2)**

Percentage of patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role.

These data are calculated using the individual project results (project audit result/project audit number \* 100). At project commencement the average was 34%, this peaked in February 2014 at 77% and then decreased slightly at project completion. The data is summarised in Figure 7 below.

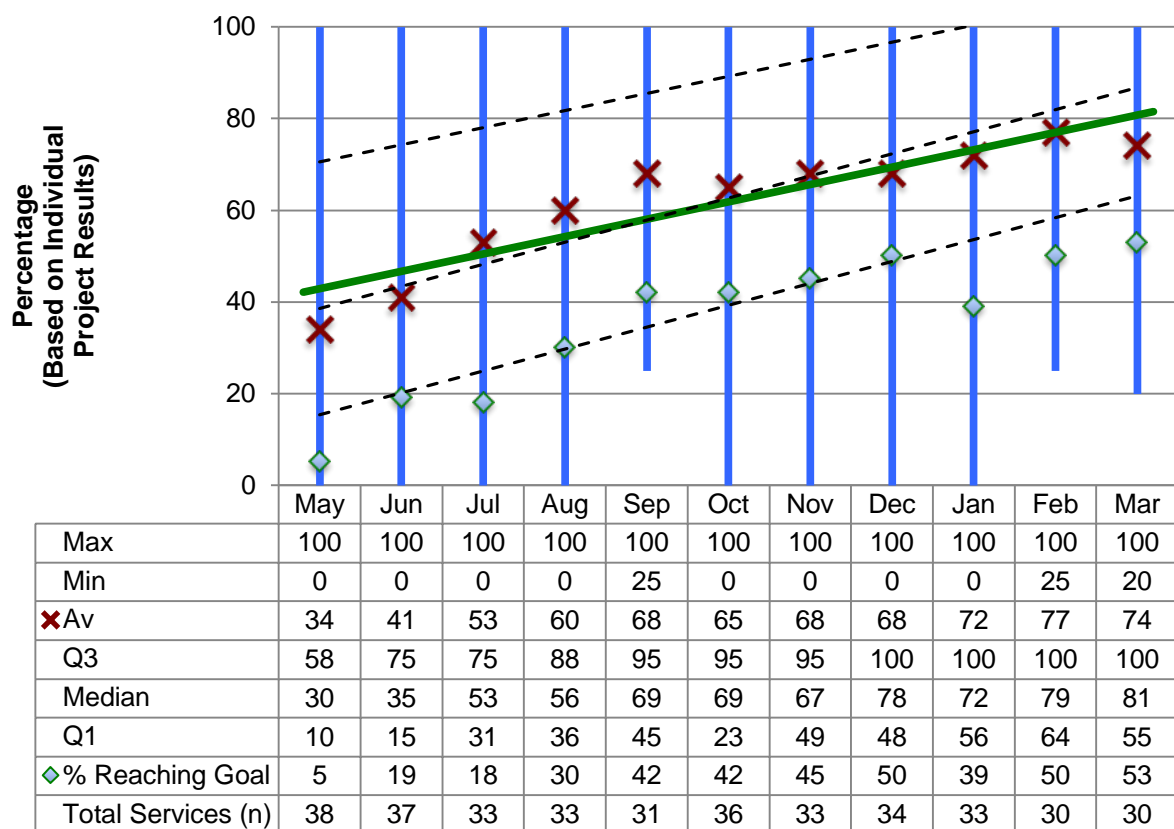


Figure 7: Percentage of patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role.

The improved results for this measure indicate a greater percentage of patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role. Analysis of the group project data for P2 supports the following conclusions:

- All measures (Q1, median, Q3 and average) of P2 showed an upward trend throughout the project.
- The individual project average for P2 improved significantly from 34% to 77% during the project but did not reach the project goal of 80%.
- More than half the services achieved the project goal.

- Only one in 20 services achieved project goal from the outset.
- While one third of services achieved a 100% return, there remained a large range (80%) between services.
- While some services continued to struggle with this performance measure towards project completion, there was still strong improvement in the median and all quartiles throughout the project.

**Percentages split by project focus for: 1) direct care projects and 2) ambulatory projects**

Figure 8 summarises the results for the average percentage of patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role by project focus. Both the direct care (inpatient) and ambulatory (community) projects have shown a steady improvement in this performance measure. Ambulatory projects achieved the project goal in January and February 2014. In contrast the inpatient care group didn't achieve the project goal but continued to improve, reaching 72% at project completion.

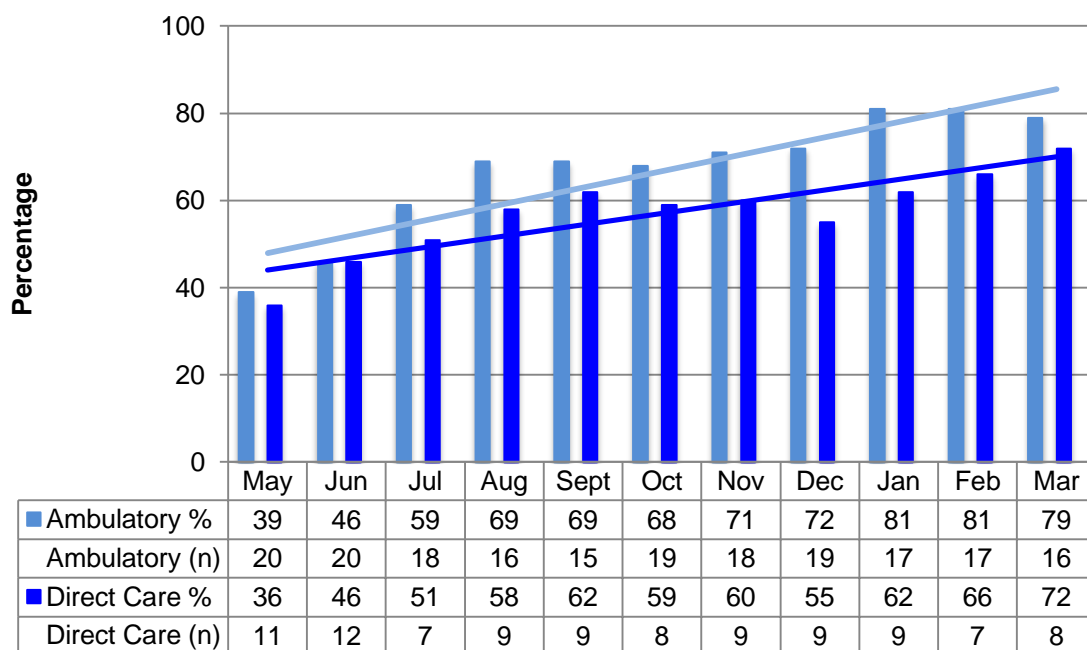


Figure 8: Average percentage of patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role by project focus.

**Question 3: Does the patient’s record evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role?**

**Performance Measure 3 (P3)**

Percentage of patient records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role.

These data are calculated using the individual project results (project audit result/project audit number \* 100). This performance measure showed an upward trend from 37% at the baseline to 78% in December 2013, but decreased slightly over the next three months. The data is summarised in Figure 9 below.

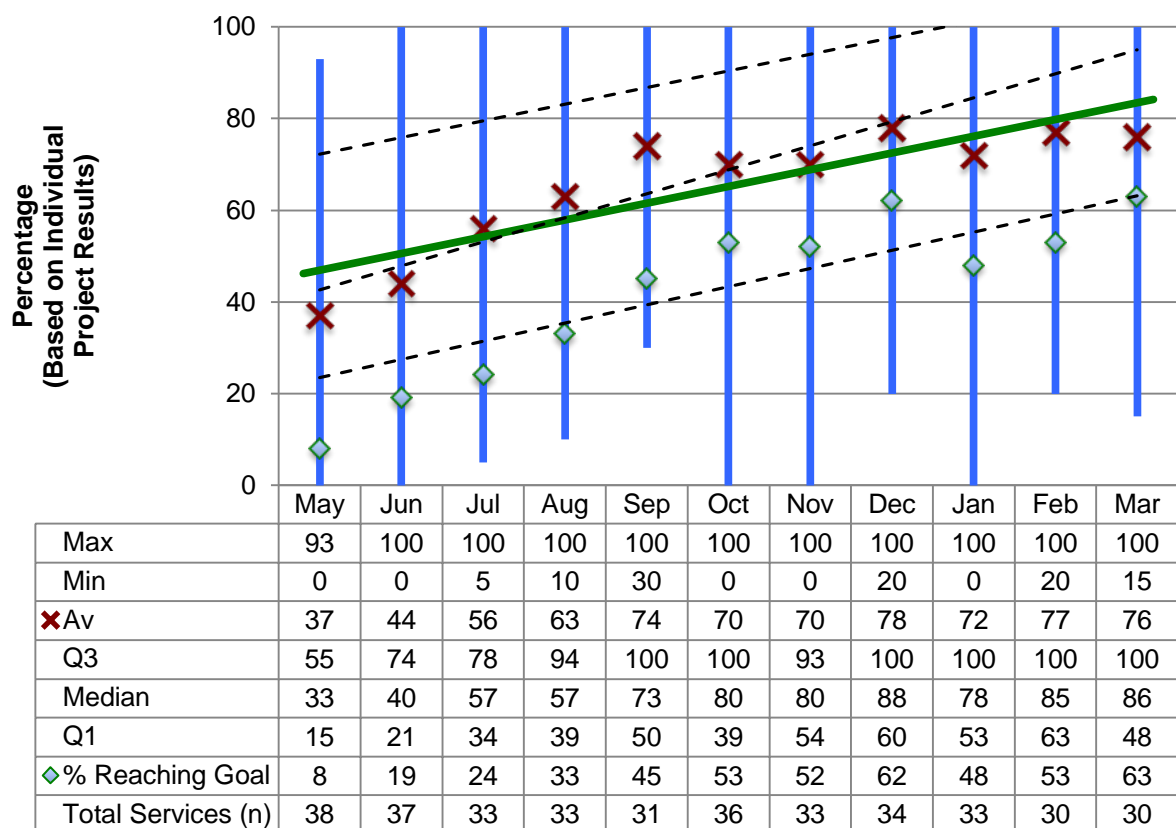


Figure 9: Percentage of patient records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role.

The results for the percentage of patient records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role improved over the project. Analysis of the group project data for P3 supports the following conclusions:

- All measures of P3 (Q1, median, Q3 and average) showed an upward trend throughout the project until December and plateaued for the remaining of the project.
- The individual project average for P3 improved from 37% to 78% during the project but did not reach the project goal of 80%.
- Only one in 13 services achieved project goal from the outset.

- Just under two-thirds of services achieved the project goal.
- While more than one third of services achieved a 100% return, there remained a large range (85%) between services.
- Some services continued to struggle with this performance measure towards project completion, but there was still strong improvement in all quartiles throughout the project.

**Percentages split by focus for: 1) direct care projects and 2) ambulatory projects**

Figure 10 summarises the average percentage of patient records with evidence that the carer(s) is aware of palliative care and other services and resources available to support their role by project focus. Both the direct care (inpatient) and ambulatory (community) projects have shown a steady increase in this performance measure. Ambulatory projects achieved the project goal from December onwards. In contrast the inpatient care group didn't achieve the project goal but continued to improve over the project reaching 71% at completion.

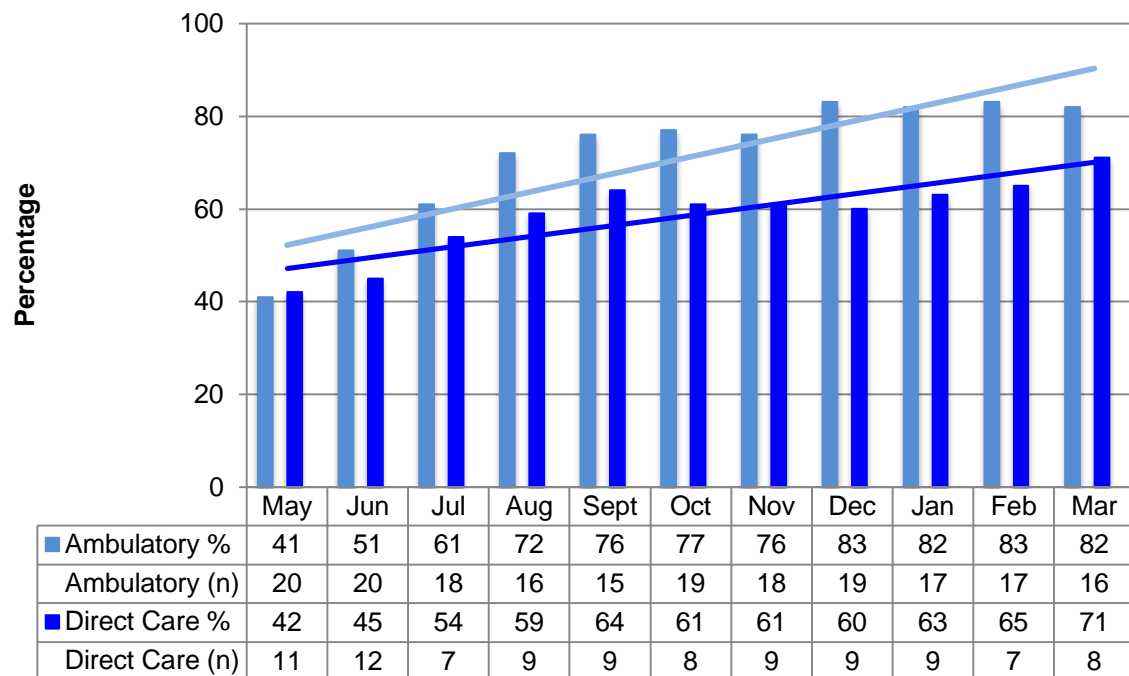


Figure 10: Average Percentage of patient records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role by project focus.

## Question 4: Does the patient’s record evidence an assessment of the carer(s) needs?

### Performance Measure 4 (P4)

Percentage of patient records with evidence of an assessment of the carer(s)’ needs (P4).

These data are calculated using the individual project results (project audit result/project audit number \* 100). While this performance measure has shown an upward trend improving from 3% at the baseline and achieving 30% at project completion it is the weakest of all the measures. However, unlike the other measures it was the only one that required fulfilment of a number of criteria in order to obtain a positive audit result. Eight criteria to be evidenced in the audit were: physical, psychological, social, cultural, financial, death preparation, bereavement needs and spiritual assessments. The project goal was not achieved and the results suggest that this area of care requires significant, ongoing improvement. A summary of the data follows in Figure 11 below.

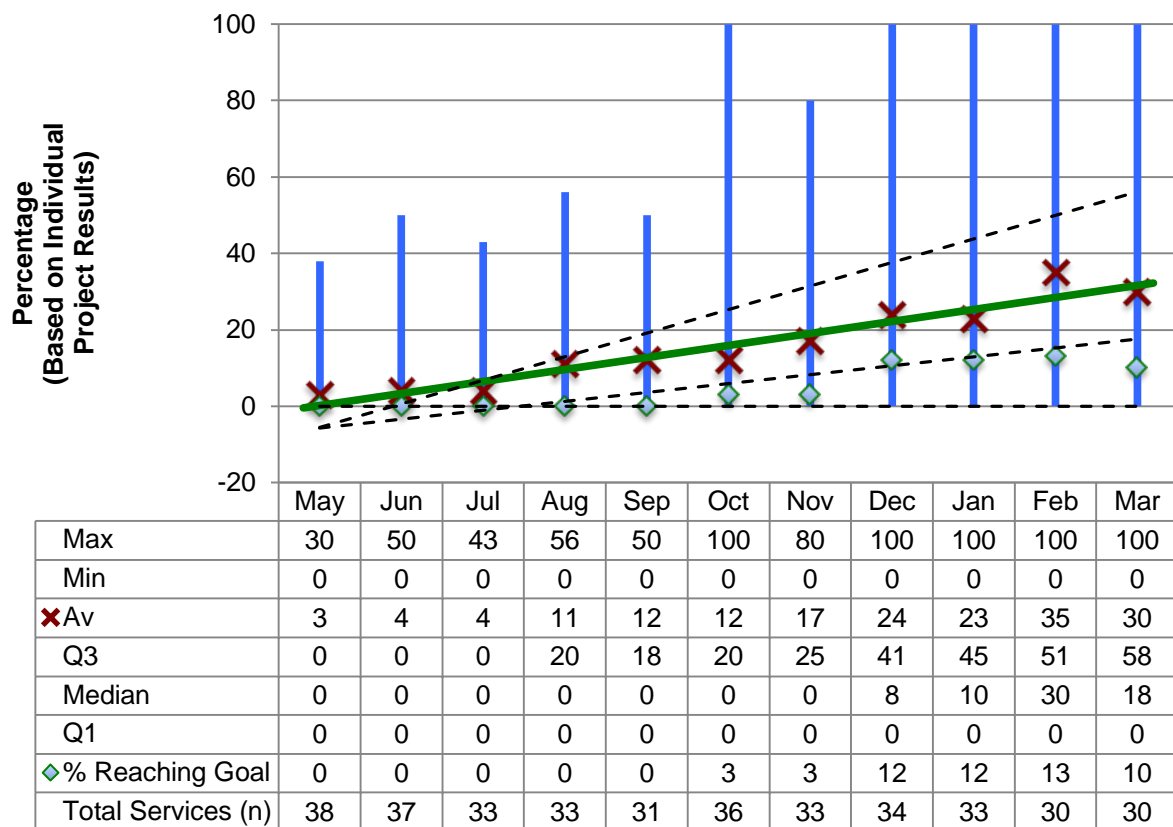


Figure 11: Percentage of patient records with evidence of an assessment of the carer(s)’ needs.

P4 was the most complicated performance measure; to be successful, all eight criteria – psychological, physical, social, spiritual, cultural, financial, death preparation and bereavement needs – had to be assessed. Analysis of the group project data for P4 supports the following conclusions:

- Although remaining weak, some measures of P4 (median, Q3 and average) showed an upward trend throughout the project.

- The individual project average for P4 improved from 3% to 30% during the project but has fallen well short of the project goal of 80%.
- No services achieved project goal from the outset.
- Only one in ten services achieved the project goal.
- Few services achieved a 100% return, an indicator that remained variable with a large range (100%) between services.
- More than one third of services continued to struggle and still recorded no success in this performance measure at project completion. However, there was still strong improvement in the median and higher quartile throughout the project.

**Assessment criteria**

There were eight audit criteria evidenced in the audit: physical, psychological, social, cultural, financial, death preparation bereavement needs and spiritual assessments. These data are calculated using the **total project results**. The psychological, physical, social, spiritual, cultural and financial criteria are in Figure 12 below.

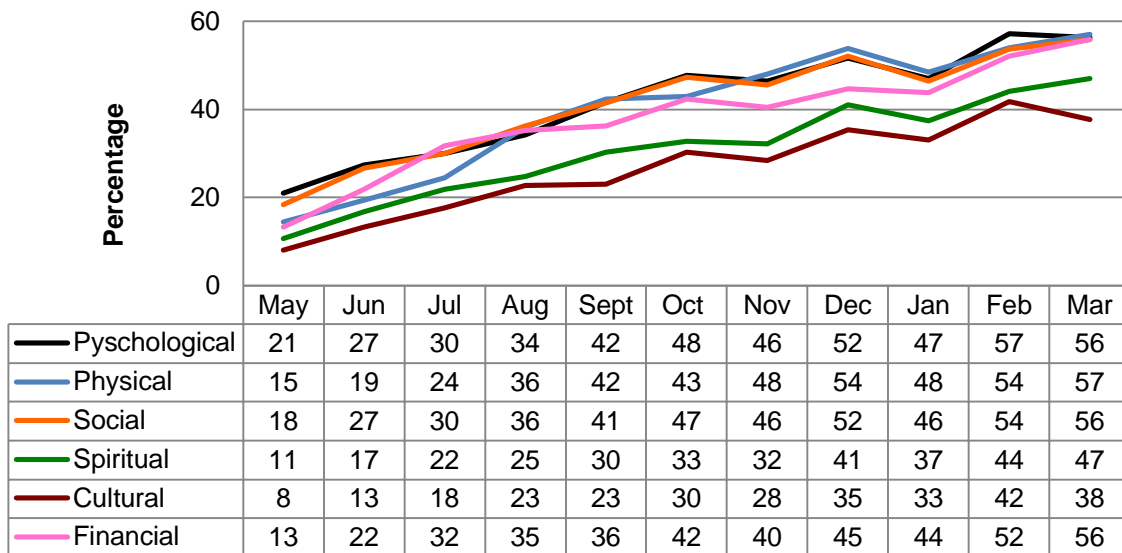


Figure 12: Comparison of holistic assessment criteria results.

All these criteria improved over the project with the weakest being “cultural”. The spiritual criterion is the second weakest area and the remainder, while still weak, were all fairly consistent. The death preparation and bereavement needs, presented in Figure 13 show similar results confirming the need for continued improvement.

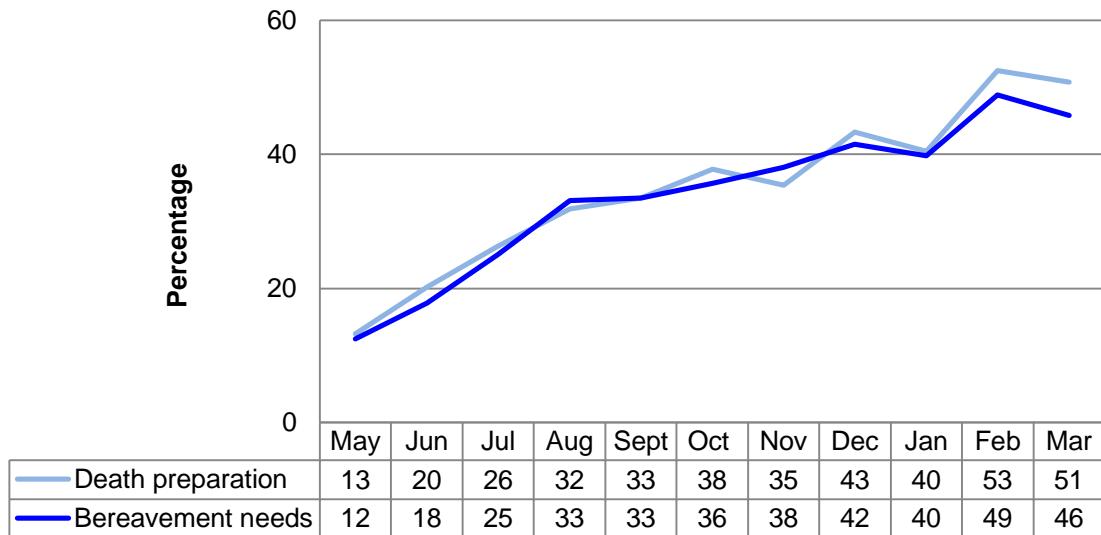


Figure 13: Comparison of holistic assessment criteria results.

While the overall performance measure result is low, Figures 8 and 9 indicate improvements, reflected in the final result for this measure. The holistic assessment of the carer(s)' needs has been a focal point of this project and is also the area that requires the most ongoing work post project. Comparison data between direct care and ambulatory projects is not conducted for this performance measure because of the vast differences in how participant services measured individual criteria.

This performance measure is critical to understanding the “holistic assessment”, the complexities of which were illuminated both in data results and teleconference discussions. One of the difficulties with this measure is the possible inconsistency across services in assessment of the eight criteria. Some services may have used “yes” or “no” categories for a criterion and others may have used a more comprehensive approach. However, assuming that an organisation consistently used the same specifications for criteria across the project, the results do show improvement. This measure requires further criteria specification for future work.

## Question 5: Does the patient’s record evidence a documented plan of action to support the carer(s)’ needs?

### Performance Measure 5

Percentage of patient records with evidence of a documented plan of action to support the carer(s)’ needs (P5).

These data are calculated using the individual project results (project audit result/project audit number \* 100). This performance measure has shown an upward trend improving from 19% at the baseline and achieving 52% at project completion. A summary of the data is in Figure 14 below.

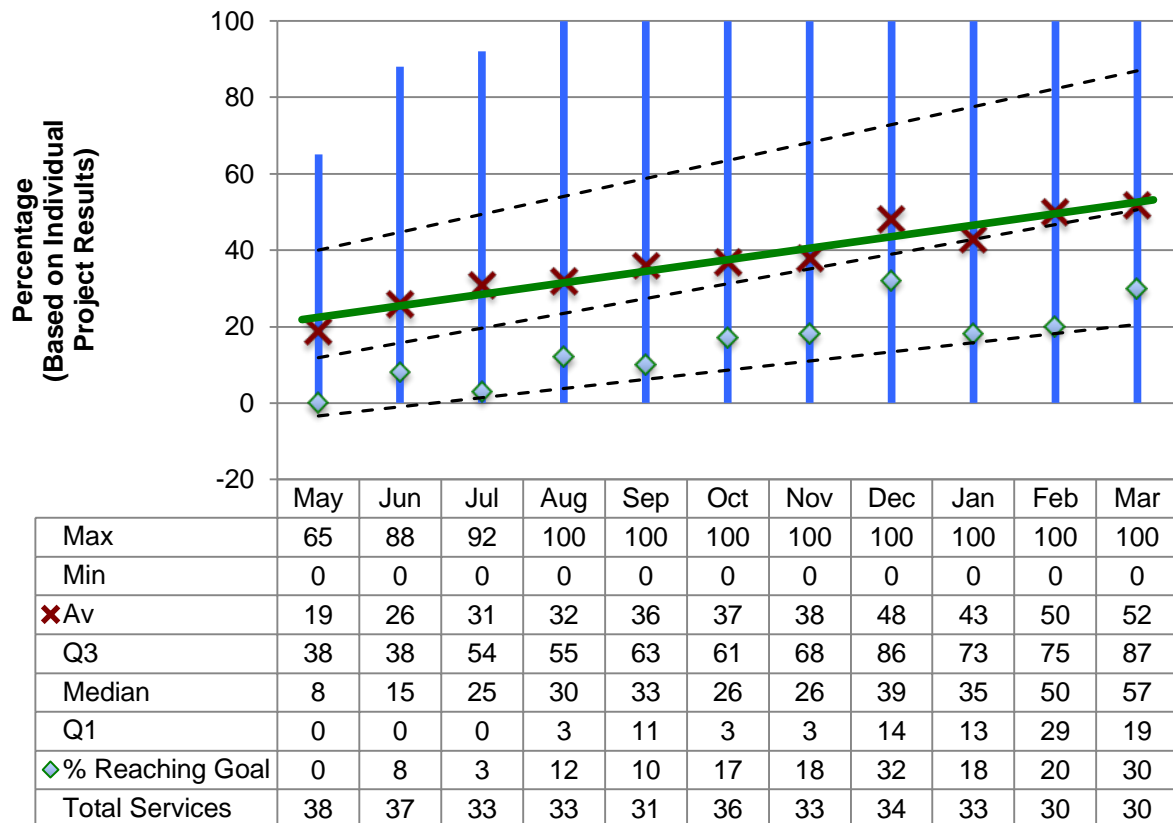


Figure 14: Percentage of patient records with evidence of a documented plan of action to support the carer(s)’ needs.

The results for the performance measure of percentage of patient records with evidence of a documented plan of action to support the carer(s)’ needs (P5) demonstrated improvement but did not reach the project goal. As the planning of action to support the carer(s)’ needs may be intrinsically dependent on initial assessment of those needs, this measure may improve as work continues on P4. Analysis of the group project data for P5 supports the following conclusions:

- P5 showed gradual improvement achieving 52% at project completion. Arguably a documented plan of action to support the carer(s)’ needs relies on completion of the holistic assessment (P4); thus the results of P4 are likely to affect this performance measure.
- Although they remained weak, all measures of P5 (Q1, median, Q3 and average) showed an upward trend over the project.



- The individual project average for P4 improved from 19% to 52% but fell well short of the 80% project goal
- No services achieved project goal from the outset.
- Nearly one in three services achieved the project goal.
- Few services achieved a 100% return, and this performance measure remained variable with a large range (100%) between services.
- More than one in eight services continued to struggle and recorded no success with this performance measure at project completion. However, there was still strong improvement in the median and all quartiles throughout.

**Percentages split by project focus for: 1) direct care projects and 2) ambulatory projects**

Figure 15 summarises the average percentage of patient records with evidence of a documented plan of action to support carer(s)' needs by project focus. Both the direct care (inpatient) and ambulatory (community) projects have shown a steady increase in this performance measure. At project completion ambulatory projects achieved 58% and direct care projects 59%, both below the project target.

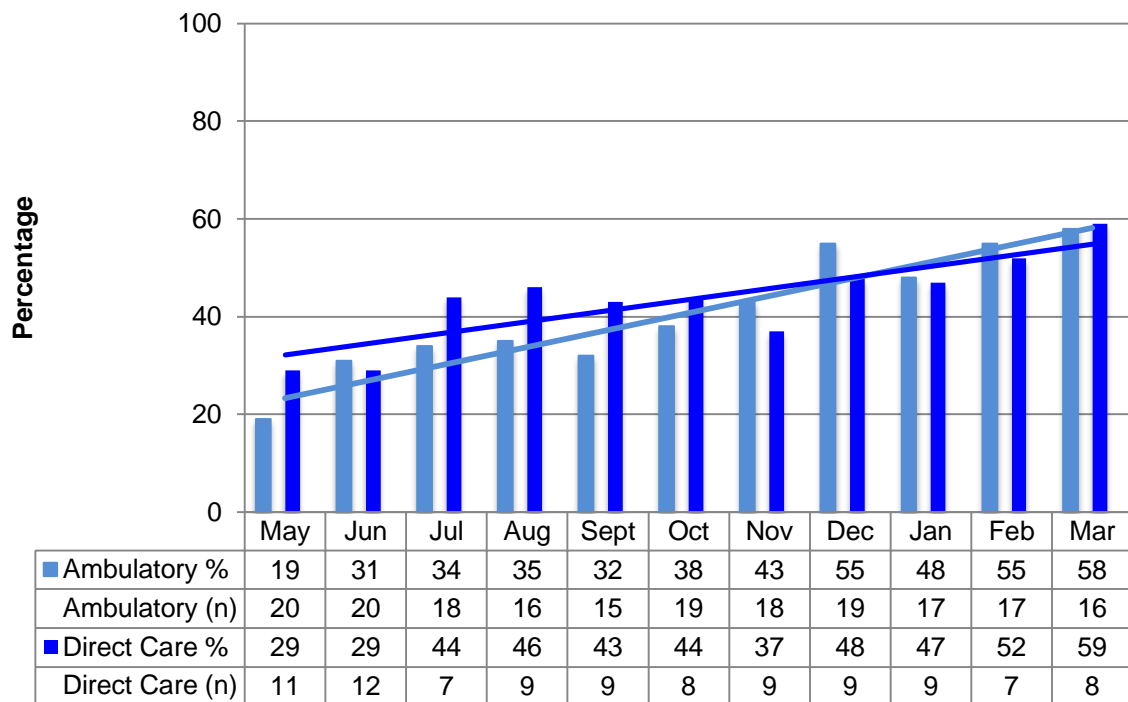


Figure 15: Average percentage of patient records with evidence of a documented plan of action to support the carer(s)' needs by project focus.

## Limitations of the evaluation

The project performance measures evaluated care delivery processes for the “carer” of palliative patients. The limitations of the quantitative data analysis are important considerations in reviewing the results of this evaluation and are discussed below:

- While all services collected the data for all performance measures it was acknowledged from the outset that some measures may not have been related to the targeted PDSA work.
- The reliability of the quantitative data cannot be confirmed.
- The validity of the quantitative data cannot be confirmed. For example, varying interpretations of terms in the performance measures (e.g. holistic, culture) may have prevailed.
- Many factors may have influenced the variation in each measure; to accurately analyse the effect of these factors, it would be necessary to statistically control them. This was not possible for the following reasons: 1) different settings were used in the project (e.g. direct care, ambulatory care); 2) services were not using the same quality strategies, 3) validity of the performance measures; and 4) inconsistency of audit approaches. It cannot be confirmed that changes in group results were attributable to the project work for each performance measure; the measures may have improved or weakened due to external factors.
- A lack of benchmarking data limits the comparison of results with previous data. Benchmarking is the use of external comparisons to understand individual service data. Individual services are able to compare their data with the group project data. However, caution is needed in any interpretative comparisons because all measures showed a large variation in the results across projects; use by participating services of different models of service delivery may have affected results.
- Study settings across the projects were different.
- Populations across different services may have been dissimilar.
- The data used in this report was secondary data submitted by different organisations. The evaluator did not collect the primary data.
- The conclusions are not applicable nationally across specialist palliative care services due to use of a convenience sample.

Recommendations outlined in the following summary reflect these limitations.

## Summary

### Performance measures achieving the project goal

The project goal for all project performance measures was 80%. The summary results in Figure 16 show that all the performance measures continued to improve from the May 2013 baseline data set until project completion in March 2014.

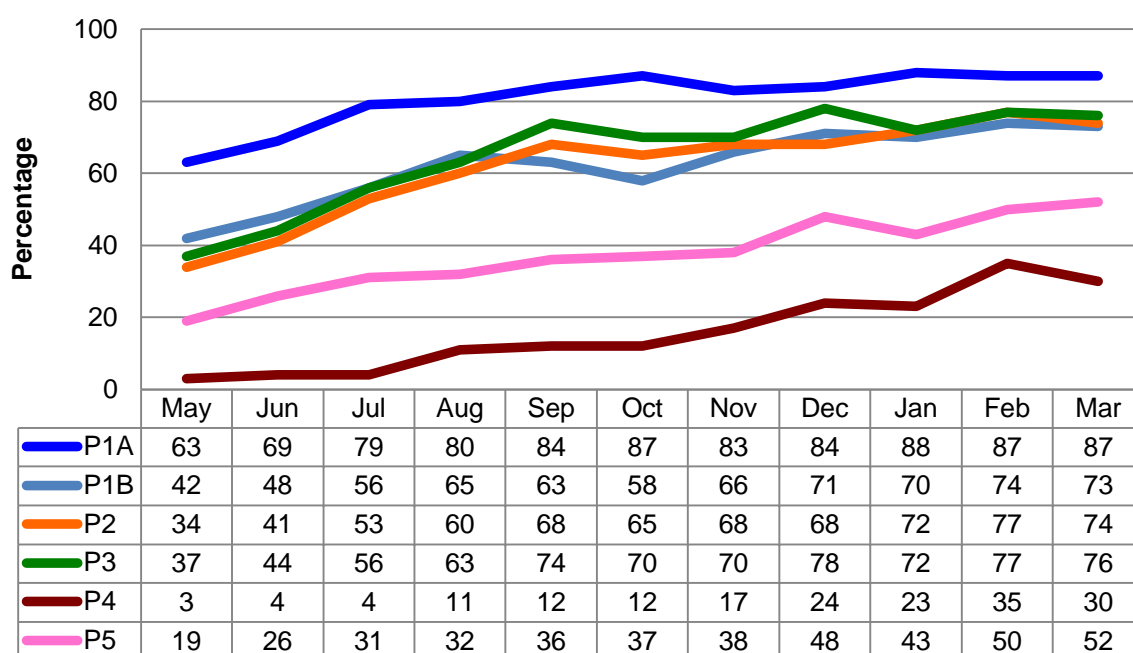


Figure 16: Summary of average percentage results for each performance measure.

Figure 16 clearly shows that the relative rank performance of each performance measure was roughly maintained throughout the project. This supports that lower performing measures reflect a higher degree of difficulty, with no quick fixes or easy interventions found. Many results appeared to plateau several months before project completion.

The percentage of patient records with evidence that the patient had identified their carer(s) (**P1A**) was the best reported performance measure from project outset and was the only measure that met (and exceeded) the project goal. Clearly, the patient identified their carer(s) in the majority of records audited.

Three performance measures: (**P1B**) The percentage of patient records with evidence that the patient had identified the carer(s)' role; (**P2**) The percentage of patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role; and (**P3**) The percentage of patient records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role; were roughly grouped together throughout the project. While these performance measures all fell just short of achieving the project goal, they exhibited solid improvement.

The percentage of patient records with evidence of an assessment of the carer(s)' needs (**P4**) was the most complicated performance measure and the results suggest that in order to achieve the project goal, ongoing improvement work is needed. To be successful, all eight criteria – psychological, physical, social, spiritual, cultural, financial, death preparation and bereavement needs – had to be assessed for this measure. While the individual project average for P4 improved significantly during the project, it still fell well short of the project goal.

The percentage of patient records with evidence of a documented plan of action to support the carer(s)' needs (**P5**) showed gradual improvement over the project period. Arguably a documented plan of action to support the carer(s)' needs relies on completion of the holistic assessment (P4); thus the results of P4 are likely to impact this performance measure. The individual project average for P5 improved markedly during the project but also fell well short of the project goal.

The data suggests that the ambulatory (community) projects performed better than direct care (inpatient) services. Comparison data was shown for direct care (inpatient) and ambulatory (community) projects for all the performance measures except P4 (The percentage of patient records with evidence of an assessment of the carer(s)' needs). There was no comparison data between direct care projects and ambulatory projects was for this performance measure because of the vast differences in the way participant services measured the eight criteria. The ambulatory group achieved the performance measure goal of 80% for P1A (reached goal and maintained goals from August 2013), P2 (achieved goal in January 2014) and P3 (achieved goal in December 2013). The two groups presented similar data for the percentage of patient records with evidence of a documented plan of action to support the carer(s)' needs; the ambulatory group achieving 58% and the direct care group 59% at project completion. While the ambulatory group showed slightly higher results across all the performance measures, both groups showed upward trends over the project. The group data were descriptive and not tested for statistical significance since projects differed greatly; hence caution is needed in making any assumptions about this outcome.

### **Services achieving the project goal**

The project goal for the percentage of individual services meeting the project goal (relative to the number of service data sets submitted) was 80%. The only performance measure to achieve the goal was P1A: Percentage of patient records with evidence that the patient has identified their carer(s). A summary of the percentage of services achieving the project goal for each performance measure is shown in Figure 17.

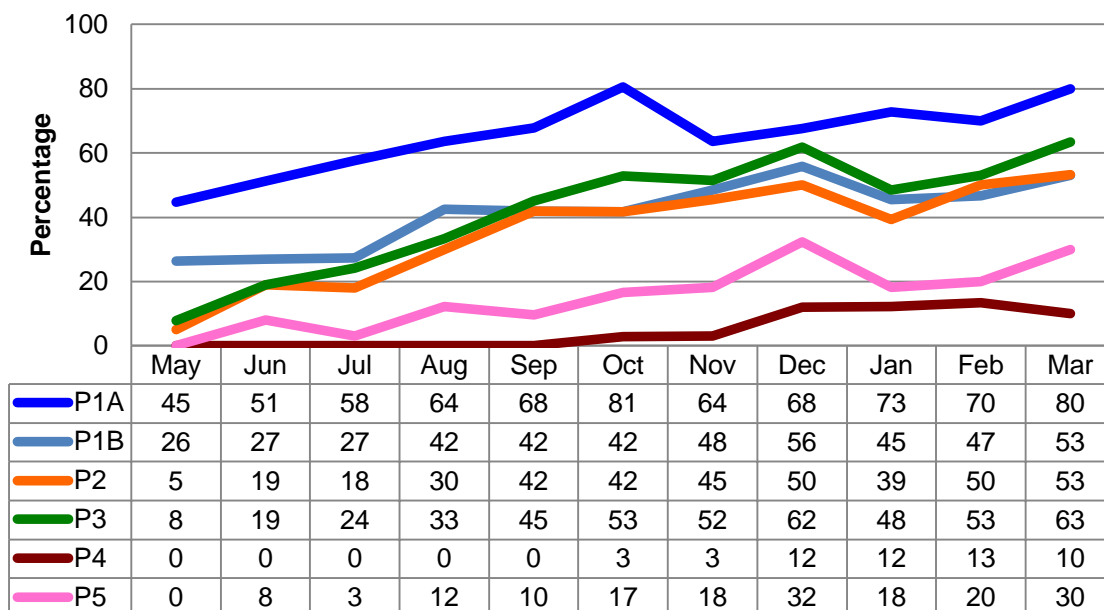


Figure 17: Percentage of services achieving the project goal for each performance measure.

The percentage of services achieving project goal is a similar rank order to the performance measures. Once again all measures improved throughout the project. The early plateauing of the performance measures noted in figure 16 is also emphasised. There were significant differences between services from the outset. Services that started the project with performance measures in the higher quartiles achieved the project goal earlier and, while the average performance also improved in those services in the lower quartiles, many continued to struggle; a significant gap remained between the higher and lower performing services throughout the project.

This disparity may help to explain the “plateau” noted in the latter months of the project. While there are no survey related comments that would explain these results, it may simply reflect the starting mix of services involved. Services that started out with a higher baseline achieved goal sooner, while those starting from a poorer position, either took longer to achieve goal or continued to struggle. As more and more services achieved outcomes above target (with many achieving 100 per cent) their impact on average improvement was nullified. The “plateau” may simply reflect this statistical artefact.

Overall, this evaluation was supported by the strong commitment of staff to the collection and submission of data for the performance measures. This data was subsequently analysed and supported results **evidencing improvement** in all performance measures. There is continued opportunity to improve the service delivery processes required to support carers. Recommendations for improving further evaluation in this area are identified below:

- The validity of the quantitative measures needs to be extensively researched before they can be reliably used in the wider palliative care setting.
- Inter-rater reliability of performance data in individual services needs to be completed in future projects.

- The identification of factors that potentially impact data variability needs to be explored in the design of performance measures.
- The need for consideration of specific work areas for individual projects as this impacts the scope of the final analysis.
- The need to consider the use of specific audit tools in the project, which would ensure consistent data collection across all projects.
- The process measures used in this evaluation do not measure “carer outcomes”. Measuring these could provide a different perspective on health care service delivery.
- A mixed methods design using qualitative and quantitative methods would provide greater insight into how care is delivered for carers. For example, the percentage of patient records with evidence of an assessment of the carer(s)’ needs provides a result but the construct of “the assessment” and why the results were low is not answered.
- Ideally, a quality improvement program should identify and address the concerns of all stakeholder groups involved in the area of care. In this project the health service provider perspective dominated; future improvement in individual service projects should broaden the stakeholder scope.

Quality improvement in services is not feasible without dedicated planning and effort. This evaluation suggests that health care practitioners have reviewed care for the carers of palliative care patients and that they advocate recognition of the importance of carers. The evaluation has evidenced improvements across all quantitative performance measures while simultaneously illuminating areas with opportunity for continued improvement. The Institute for Healthcare Improvement Breakthrough Series collaborative model used in this project has helped facilitate participating services make improvements (Institute of Healthcare Improvement, 2003). The participating services have actively engaged in discussion, review and implementation data strategies to identify, assess and evaluate care delivery processes for carers of palliative patients.

## Appendix 1: Expert Reference Panel Membership

Surname	First Name	Position	Service	State
Burridge	Letitia	Postdoctoral Research Fellow	University of Queensland	QLD
Breen	Lauren	ARC Discovery Early Career Researcher and Senior Lecturer	Curtin University	WA
<b>Aoun</b>	Samar	Professor & Director	WA Centre for Cancer and Palliative Care	WA
<b>Yates</b>	Patsy	Professor	School of Nursing & Midwifery, Queensland University of Technology	QLD
Hudson	Peter	Director	Centre for Palliative Care	VIC
Wright	Robyn	Quality Manager	Banksia Palliative Care	VIC
Grace	Marnie	Quality & Informatics Coordinator	South Eastern Palliative Care	VIC
Cavenagh	John	Senior Staff Specialist	Calvary Mater Newcastle	NSW
Lawler	Lois	Social Worker	Gold Coast Health Service (Palliative Care)	QLD
Douglas	Carol	Director	Royal Brisbane & Womens Hospital	QLD
Swetenham	Kate	Manager	Southern Adelaide Palliative Care Services	SA
Gore	Fran	Nurse Manager	Mercy Palliative Care	VIC
Hatton	Ian	Director of Nursing	St Vincents Melbourne	VIC
Bramwell	Michael	Manager Committee Member	Melbourne Citymission Palliative Care Palliative Care Victoria	VIC
Allsop	Andrew	Support Manager - Psychosocial and Spiritual Service President	Silver Chain Hospice Care Service Palliative Care WA	WA
Farrance	Melissa	Research Officer	Carers Australia	ACT
Athan	Sophy	Board Member	Health Issues Centre	VIC
Tieman	Jen	CareSearch Director	Flinders University	SA
Connelly	Jane	Quality Improvement Facilitator Committee Member	Palliative Care Outcomes Collaboration (PCOC) Palliative Care NSW	NSW
Forster	Rosie	Advisor	Independent	VIC
Henderson	Amanda	Evaluator	Independent	QLD

## Appendix 2: Evaluation Questions

Evaluation Question	Project Aim	Guideline Reference
Does the patient's record evidence that the patient has identified a carer(s) and the carer(s)' role?	Aim 1: All patients will have identified a carer	1,2
Does the patient's record evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role?	Aim 2: All carers will have discussed the caring role with a health professional and agreed to be the patient's carer	3
Does the patient's record evidence that the carer is aware of palliative care and other services and resources that are available to support their role?	Aim 3: All carers will have a needs assessment completed and a documented plan of action.	6
Does the patient's record evidence an assessment of the carer(s)' needs?	Aim 3: All carers will have a needs assessment completed and a documented plan of action	8
Does the patient's record evidence a documented plan of action to support the carer(s)' needs?	Aim 3: All carers will have a needs assessment completed and a documented plan of action	9
<b>Guideline reference (Hudson et al., 2010a, pp. 8-9)</b>		
<p><b>Guideline 1.</b> "Once a patient has agreed to receive palliative care, inform the patient that the role of palliative care is also to support their family caregiver(s). The family caregiver(s) will be a person(s) who the patient perceives to be their most important support person(s). This may be a family member, partner or friend and may not necessarily be his/her next of kin."</p>		
<p><b>Guideline 2.</b> "Ask the patient to identify the primary family caregiver(s). Where only one family caregiver is identified ask the patient if there is another family member/friend who may be willing to be approached and act as an additional family caregiver. Discuss the patient's preferences for the involvement of the family caregiver in medical and care planning discussions and note this in the medical record/care plan."</p>		
<p><b>Guideline 3.</b> "Confirm with the family caregiver(s) that they understand the patient has nominated them for this role. Explain the typical role and responsibilities of 'family caregiver' and confirm that they are willing to accept this responsibility and note this in the medical record. Discuss any concerns that the family caregiver may have in accepting this role (including possible conflicts with other family members)."</p>		
<p><b>Guideline 6.</b> "Explain to the family caregiver(s) what services and resources can be provided by the palliative care service so that realistic expectations are established."</p>		
<p><b>Guideline 8.</b> "Conduct a needs assessment with the family caregiver(s). This should include psychological and physical health, social, spiritual, cultural, financial and practical elements."</p>		
<p><b>Guideline 9.</b> "Once the family caregiver(s)' needs are assessed, develop a plan of action with involvement from the family caregiver(s). Initiate the appropriate interventions as pertinent."</p>		

Table 1: Evaluation questions



## Appendix 3: Project Definitions

NSAP has defined “assessment” and “plan of care” for the context of this Project as:

**Assessment:** The conducting of an assessment of a carer to identify their needs. This can be through the use of assessment tools (e.g. a validated tool such as the home caregiver need survey).

**Plan of Care:** The provision of interventions for the carer.

The following definitions, used in this Project, are cited from the “Standards for Providing Quality Palliative Care for all Australians” (Palliative Care Australia, 2005, p. 11):

**Caregiver:** (The “carer” in the NSAP: CIP project uses the same definition as the “caregiver” defined below.)

“The caregiver is generally in the close kin network of the patient and is usually self identified, eg spouse, partner, adult child, parent or friend. This person undertakes to provide for the needs of the patient and may take on additional tasks of a technical nature to provide ongoing care for the patient, eg administration of medications. The primary caregiver provides the primary support role for the patient at all levels of need. The term primary caregiver may include more than one individual, for example the mother and father when the patient is a child.”

**Life limiting illness:** “The term life limiting illness is used here to describe illnesses where it is expected that death will be a direct consequence of the specified illness. This definition is inclusive of illnesses of both a malignant and nonmalignant nature. A life limiting illness might be expected to shorten an individual’s life. This differs from chronic illness where, even though there may be significant impact on the patient’s abilities and quality of life, there is likely to be a less direct relationship between the illness and the person’s death.”

**Patient:** “The word patient is used to describe the primary recipient of palliative care. “People with a life limiting illness” is also used in this document to describe the same group of people where the context and language flow allow for it.”

**Support for Carers:** The definition of support for carers for this project is as follows:

“Support for carers who are assisting a spouse/partner/relative/friend requiring palliative care, which may incorporate practical, educational, psychological, spiritual, financial or social strategies (based on unmet needs and a desire by the carer/s for assistance) with the intention of enhancing the carer’s capacity to undertake their role, respond to its challenges and maintain their own health (before and after their relative/friend’s death)”(Hudson P, Payne S, 2009, p. 284).

## Appendix 4: Performance Measures

Do palliative care assessments evidence that the patient has identified a carer(s) and the carer(s)' role?

Performance Measure 1 (P1A): Identified carer	
Parameters	Description
<b>Outcome measure</b>	% of patient records with evidence that the patient has identified their carer(s)
<b>Definition</b>	Patient records with evidence that the patient has identified a carer(s) of all records
<b>Numerator</b>	Number of patient records with evidence that the patient has identified their carer(s)
<b>Denominator</b>	The last 20 patients admitted to the service in the current month (if less than 20 patients are admitted within the month then a census is used)
<b>Goal</b>	80 % of patient records with evidence that the patient has identified their carer(s)
<b>Data source</b>	Patient record audit: The patient has identified their carer(s) and this is documented in the patient's record*

\*NB: If the patient has identified **NO** carer then this record is excluded from the audit data and the rest of the performance measures.

**Do palliative care assessments evidence that the patient has identified a carer(s) and the carer(s)' role?**

<b>Performance Measure 1B (P1B): Carer's role</b>	
<b>Parameters</b>	<b>Description</b>
<b>Outcome measure</b>	% of patient records with evidence that the patient has identified the carer's role
<b>Definition</b>	Patient records with evidence that the patient has identified the carers(s)' role of all records
<b>Numerator</b>	Number of patient records with evidence that the patient has identified the carer(s)' role
<b>Denominator</b>	The last 20 patients admitted to the service in the current month (if less than 20 patients are admitted within the month then a census is used)
<b>Goal</b>	80 % of patient records with evidence that the patient has identified the carer(s)' role
<b>Data source</b>	Patient record audit: The patient has identified the carer(s)' role and this is documented in the patient's record

**Does the patient’s record evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role?**

<b>Performance Measure 2 (P2)</b>	
<b>Parameters</b>	<b>Description</b>
<b>Outcome measure</b>	% of patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role
<b>Definition</b>	Patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role
<b>Numerator</b>	Number of patient records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role
<b>Denominator</b>	The last 20 patient records admitted to the service in the current month (if less than 20 patients are admitted within the month then a census is used)
<b>Goal</b>	80 % of records with evidence that a health care professional has discussed the caring role with the carer(s) and that the carer(s) has agreed to the role
<b>Data source</b>	Patient record audit

**Does the patient’s record evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role?**

<b>Performance Measure 3 (P3)</b>	
<b>Parameters</b>	<b>Description</b>
<b>Outcome measure</b>	% of patient records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role
<b>Definition</b>	Patient records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role of all records
<b>Numerator</b>	Number of patient records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role
<b>Denominator</b>	The last 20 patient records admitted to the service in the current month (if less than 20 patients are admitted within the month then a census is used)
<b>Goal</b>	80 % of records with evidence that the carer(s) is aware of palliative care and other services and resources that are available to support their role
<b>Data source</b>	Patient record audit

**Does the patient’s record evidence an assessment of the carer(s)’ needs?**

<b>Performance Measure 4 (P4)</b>	
<b>Parameters</b>	<b>Description</b>
<b>Outcome measure</b>	% of patient records with evidence of an assessment of the carer(s)’ needs
<b>Definition</b>	Patient records with evidence of an assessment of the carer(s)’ needs of all records
<b>Numerator</b>	Number of patient records with evidence of an assessment of the carer(s)’ needs
<b>Denominator</b>	The last 20 patient records admitted to the service in the current month (if less than 20 patients are admitted within the month then a census is used)
<b>Goal</b>	80 % of records with evidence of an assessment of the carer(s)’ needs
<b>Data source</b>	<p>Patient record audit to identify ALL the following determinants in the assessment:</p> <ul style="list-style-type: none"> <li>• Psychological</li> <li>• Physical</li> <li>• Social</li> <li>• Spiritual</li> <li>• Cultural</li> <li>• Financial</li> <li>• Death preparation</li> <li>• Bereavement needs</li> </ul>

**Does the patient’s record evidence a documented plan of action to support the carer(s)’ needs?**

<b>Performance Measure 5 (P5)</b>	
<b>Parameters</b>	<b>Description</b>
<b>Outcome measure</b>	% of patient records with evidence of a documented plan of action to support the carer(s)’ needs
<b>Definition</b>	Patient records with evidence of a documented plan of action to support the carer(s)’ needs
<b>Numerator</b>	Number of patient records with evidence of a documented plan of action to support the carer(s)’ needs
<b>Denominator</b>	The last 20 patient records admitted to the service in the current month (if less than 20 patients are admitted within the month then a census is used)
<b>Goal</b>	80 % of records with evidence of a documented plan of action to support the carer(s)’ needs
<b>Data source</b>	Patient record audit

## Appendix 5: Final Participant Evaluation Comments (March 2014)

The following statements are examples of verbatim comments made by participants in the final survey submitted in March 2014. The comments are grouped into general themes including: data collection; validity of the performance measures; data analysis; documentation; and usefulness of the data.

### Data collection

- *Very time consuming*
- *Monthly data collection can be quite time intensive. Improvements have continued for our service though*
- *Challenging at times for staff to do the assessments on a routine basis. On-going Education and encouragement continues. The project has proven to be beneficial, with increased awareness to capture all the needs of the Carer*
- *Have been lucky to have support from team to collect data across.... Given smaller than average patient numbers was hopeful our upward trend would be higher at the end of the project, but able to see this would be the case if [the] data collection period was longer than one month. Thank you*
- *Frustrating yet challenging to encourage recording of assessments. We feel we have made great headway however with this....*
- *The collecting process was one that took more time than we anticipated during the life of the project. Also, the makeup of the team changed which meant interruptions to education and support for the staff with regards to the carer's role and support. However, it has been an interesting experience, and the results are encouraging for us, with our emphasis being on the identification of the main carer and the inclusion of this as a mandatory care plan item*
- *Data collection is time consuming but necessary in order to get baseline and see improvements. Important for arguing any case for QI strategies organisationally*
- *Interesting-Experience around data and feedback to staff*
- *One of the key issues with data collection that influenced results was 'timing' of the audit. Comprehensive admission information is collected over weeks, not one visit. This was clearly evidenced in audit results of those patients who were admitted to the service late in the data collection month, where it was never attainable to meet the entire PI at this time. On admission the needs of carers is often secondary to the immediate needs of the patient. The carer's focus is often always on patient needs. Thus there is a process to meet the needs of the patient first, as this often shifts the needs of the carer if the person they are caring for is symptomatically well managed. The other primary difficulty with the data collection was around PI 4, where it is almost impossible to meet all 8 criteria within the first few weeks of admission. Service delivery and care should always be consumer focused and this was evidenced by many of the carers not wanting to explore the death preparation and bereavement needs in the early part of their care trajectory. It is critical we do not lose the focus of timely, individualised information and intervention*
- *Data fairly easy to collect as the project progressed*
- *Data collection was onerous for our team due to the clinical record system utilised - staff had to manually search through records to gather data. Our team indicate their interpretation of the questions at the point of base line data collection was different to how they interpreted it from June onwards. We will continue to audit the completion of carer needs assessments in an on-going way but will review the data we are capturing to try and make it more manageable for staff to access and also sustainable in an on-going way. It will become part of our on-going audit schedule*



### Validity of the performance measures

- *In the beginning a collection of data was not accurate as we were using patient information scanned into a filing system, which was not always completed. Once we changed to auditing the patient's home record we were able to collect accurate data. Late referrals from admission to death did not allow for admission documentation to be completed from the community team as they were often still an inpatient in the hospice setting or moved from community to hospice for terminal care so for the sake of the audit it was incomplete.*
- *Very useful in the evaluation and audit of our documentation and tools that we use evaluation questions clear and the use of the excel spread sheet has given us our own service data with clear trends of improvement in the documentation*

### Data analysis

- *Importance of a guideline for audits at the outset; 2. In our project it was difficult to make sense of the data as there seemed to be no clear trend; 3. Useful to have teleconferences with [X] about the data and its analysis*

### Documentation

- *In the situation where a carer had not been assessed using the carer assessment form, documentation continued to be ad hoc and often difficult to discern within the patient notes*

### Usefulness of the data

- *Collecting and analysing the data helped us to understand the deficiency in our service. It also helped us explaining to the rest of the team the need of changes in the way we assess carers and how to improve the service*
- *Has been very helpful and insightful being provided with the tools and feedback in order to achieve longevity for the project*
- *The importance of keeping on track with action plans and meeting dates. •Clear documentation and communication of the carer/s needs •Acknowledge and being mindful of changing needs of carers; and adjusting your action plans accordingly Our monthly graphs showed improvement in most or all of the areas we wanted to focus on*
- *Good learning experience, great for gathering ideas from others*
- *Useful project to be involved in*
- *Compliance with use of assessment tool has improved - enabling referrals to Social Worker re carers' needs*
- *Has led to other quality improvement projects (weekly MDT meeting for community patients) Outcomes to be used as basis for communication skills program for 2014 for specialist palliative care staff Difficulty at times retrieving charts...*
- *This has been a long and difficult project but it has highlighted areas where improvement is required so we can show that we do support our carers, something we've always done but may not have the evidence to prove it before*
- *Initially challenging once data collection commenced due to interpretation of questions; seemed simple but can be ambiguous once tested, eg PATIENT identifying a carer (we have many late referrals where patient too unwell to ID carer though assessment completed; data could not be used). ... good to see positive trends forming; easy to see/anticipate where systems fall down*
- *The project has provided valuable insight into how well we assess and provide support to caregivers through the process of collecting and analysing our data*

## References

- Hudson, P., Remedios, C., Zordan, R., Thomas, K., Clifton, D., Crewdson, M., Hall, C., Trauer, T., Bolleter, A., and Clarke, D. (2010a). *Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients*. Centre for Palliative Care, St Vincent's Hospital Melbourne: Melbourne, Australia.
- Hudson, P., Graham, T., Grande, G., Ewing, G., Payne, S., Stajduhar, K and Thomsas, K. (2010b), A systematic review of instruments related to family caregivers of palliative, care patients, *Palliative Medicine*, 0(00), 1-13
- Hudson P, Payne S. *The future of family caregiving: research, social policy and clinical practice*. In: Hudson P, Payne S, editors. *Family Carers in Palliative Care: A guide for health and social care professionals*. Oxford: Oxford University Press, 2009:277 - 303.
- Institute of Health Care Improvement. (2003). *The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement*. IHI Innovation Series white paper. Boston: Institute for Healthcare Improvement. (Available on [www.IHI.org](http://www.IHI.org))
- National Standards Assessment Program. (2011). *National Quality Report*. Palliative Care Australia: Canberra.
- Palliative Care Australia. (2005). *The Standards for providing quality palliative care for all Australians* (4th edn.). Canberra: Palliative Care Australia.
- Palliative Care Australia. (March 2011). *NSAP National Quality Report December 2010*. Canberra: Palliative Care Australia.
- Palliative Care Australia. (2012). *An evaluation of the National Standards Assessment Program (NSAP), Collaborative Improvement Project: Assessment and Care Planning*. Canberra: Palliative Care Australia. Retrieved from <http://www.caresearch.com.au/caresearch/LinkClick.aspx?fileticket=w120A6Oyp7g%3D&tabid=2416>