The Standard
Newsletter
NSAP

NSAP update

Welcome to the 3rd edition of 'The Standard' newsletter.

We have now moved into the formal pilot phase of the NSAP project and have 31 hugely enthusiastic and motivated services user-testing the NSAP tools, resources and processes before we proceed to full implementation of the Program in March 2009. The national project team is looking forward to receiving and acting upon the pilot services' advice to ensure we have a program that is both meaningful and achievable at service level. A full list of the pilot sites is provided in this newsletter – along with a short profile of two pilot sites. We look forward to providing further profiles of services participating in the pilot in future editions of 'The Standard'.

In this edition we also provide an update of NSAP activities and report on a well received national meeting of pilot sites in Sydney in early September and follow up regional training workshops in each of the NSAP Regions.

This edition also includes a summary report of the National Quality Forums. A full report will be available shortly on the Standards' webpage. Thank you again to all of the busy clinicians, managers and quality improvement staff who attended these meetings.

If you would like further information on NSAP contact the NSAP national project team at **nsap@palliativecare.org.au**

The pilot

NSAP has proven to be extremely well received amongst the palliative care sector with 31 services signed up to participate in the pilot.

The pilot phase is designed to test the self-assessment component of NSAP before it is rolled out on a national scale. Pilot sites will undertake the self-assessment component to ensure useability and effectiveness of the tools which underpin NSAP. The results of the self-assessment will be shared with PCA and other pilot sites to allow for a thorough evaluation and review to take place. Pilot sites are also encouraged to adopt a community of practice approach, engaging together as a network to support each other, share ideas and problem solve.

The 31 services participating in the pilot are from rural, regional and metropolitan Australia. A list of these services is provided in table 1 below.

The pilot will run from October 2008 until January 2009. This 16 week pilot involves services forming a multi-disciplinary self-assessment team that will work through each of the 'NSAP steps' to assess themselves against the PCA *Standards for improving quality palliative care for all Australians*. After assessing themselves against the Standards,

Inside

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the team will decide on a rating of low, medium or high priority and from this develop a quality improvement action plan to address those Standards that are of high to medium priority.

To assist services in their self-assessment, the NSAP team has developed a series of audit tools that can provide a valuable source of evidence to use in their assessment against the Standards. These audit tools include a Documentation audit, a Patient Interview audit and a Family Evaluation of Palliative Care audit. Services have also been provided with a detailed list of other evidence sources that may assist them in making an assessment against each Standard.

After the pilot both the NSAP process and resources (the audit tools and workbooks) will be evaluated and reviewed based on feedback from pilot services. The final versions of these will be made available from March 2009 to all specialist palliative care services who wish to participate in the National Standards Assessment Program.

Table 1. List of Services participating in the NSAP Pilot.

Service	Suburb	State
Cessnock Singleton Palliative Care Service, Hunter New England Health Service	Cessnock	NSW
Sacred Heart Palliative Care Service, St Vincent's Hospital, Sydney	Darlinghurst	NSW
Department of Palliative Care, Calvary Mater Newcastle, Little Company of Mary Health Care	Warabrook	NSW
Albury Mercy Palliative Care, Mercy Health and Aged Care	Albury	NSW
Shoalhaven Palliative Care Service, SESIAHS	Berry	NSW
Tamworth Community Health, Hunter New England AHS	NEMSC Tamworth	NSW
Richmond Specialist Palliative Care, NCAHS & SVH	Lismore	NSW
Calvary Health Care Sydney, Little Company of Mary Health Care	Kogarah	NSW
Territory Palliative Care - Top End, Royal Darwin Hospital	Casuarina	NT
Palliative Care, Royal Brisbane and Women's Hospital	Herston	QLD
Palliative Care Service, Gold Coast Health Service District	Southport	QLD
Brisbane South Palliative Care Service, QLD Health	Eight Mile Plain	QLD
Mount Olivet Palliative Care Services, Mount Olivet Community Services	Kangaroo Point	QLD
Sunshine & Cooloola Coast Palliative Care Service, QLD Health	Nambour West	QLD
Mount Isa District Palliative Care Service	Mount Isa	QLD
Modbury Palliative Care, Modbury Hospital	Modbury	SA
Mercy Palliative Care, Mercy Health and Aged Care	Sunshine	VIC
Eastern Palliative Care	Nunawading	VIC
Banksia Palliative Care Service	Ivanhoe	VIC
South East Palliative Care	Cranbourne	VIC
Northeast Health Wangaratta Palliative Care	Wangaratta	VIC
Pain and Palliative Care, Peter MacCallum Cancer Centre	East Melbourne	VIC
Gandarra Palliative Care Unit, Ballarat Health Services	South Ballarat	VIC
South West Health Care: Palliative Care: Regional, South West Healthcare	Warrnambool	VIC
Caritas Christi Hospice, St Vincent's Health, Melbourne	Kew	VIC
Maryborough District Health Service	Maryborough	VIC
Silver Chain Hospice Care Service, Silver Chain Nursing Association	Osborne Park	WA
Peel Community Palliative Care, South Metro Area Health Service	Pinjarra	WA
Glengarry Hospital (Sandalwood), Ramsay Health	Duncraig	WA
Murdoch Community Hospice, St John of God	Murdoch	WA
St John of God Hospital Bunbury Palliative Care Service	Bunbury	WA

Profiles from pilot sites

In this edition we have a profile from St John of God Hospital Bunbury Palliative Care Service in Bunbury WA and the Palliative Care Service of Gold Coast Health Service District in Queensland. We asked services to provide an overview of their service and why they are participating in the NSAP Pilot.

St John of God Hospital Bunbury Palliative Care Service - WA

The palliative care service run by St John of God Hospital in Bunbury is co-located with the regional public hospital.

We are a palliative care service that has 4 dedicated palliative inpatient beds. We also have a community service and an on call service 24 hours a day. A visiting specialist supports the GPs in managing their palliative case loads. Our multi-disciplinary team uses a collaborative approach to all our clients.

We decided to join NSAP because it looked like an exciting opportunity to be part of a national pilot that's aim is to improve palliative care services for all Australians. We are currently running a service that to my knowledge has not been measured before and NSAP will hopefully support and supply the validated tools necessary to do this and I feel its important to be part of a national approach to the concept of quality improvement.

Palliative Care Service, Gold Coast Health Service District - QLD

Our service is located at the southern coastal end of Queensland and borders on to northern NSW. We serve a population of approximately 500,000 with a larger than average proportion of retirees and elderly patients.

Our service consists of a busy consultancy service across two hospitals (Southport >700 beds and Robina 250 beds), an inpatient unit of 20 beds with an occupancy rate of well over 90% (commonly with a waiting list) and a fledgling community specialist service (one liaison nurse) that depends largely on external help from area GPs and various NGO nursing services. We currently have two specialist consultants, two specialist community nurses who cover both consultancy and community liaison, and a non-specialist registrar and an intern who work in the inpatient unit. We also have 25 nurses or enrolled nurses who work in the inpatient unit. It is an extremely busy service with a rapidly growing referral base.

We are keen to participate in NSAP because we wanted to be able to accurately reflect on the current perception of our patients and their families towards the care we provide. We want to incorporate the patient and family feedback into our future planning and our continuous quality improvement processes. We also wanted to review the measurement tools we currently use to make sure that they were validated nationally and internationally. NSAP provides us with a formal reason to do this through the documentation audit process.

We hope to be able to form an ongoing inter-disciplinary oversight team for the palliative care service. We want to reinforce the culture of evidence-based, patient and family focused care and develop sound reflective and continuous quality improvement processes based on the evidence provided from patient and family feedback. We hope to also be able to develop bench-marking and peer-review processes that we can use to evaluate our service provision.

Working with the sector

Initial pilot workshop in Sydney – 4th September

PCA launched the pilot of NSAP at an introductory workshop in Sydney on Thursday 4th September 2008. Representatives from each of the pilot sites were invited to participate in the workshop, which included presentations from:

• Professor Patsy Yates (PCA Executive Committee Member, Director Centre for Palliative Care Research and Education (CPCRE))

• Bradley Greer (Department of Health and Ageing) and

• Jane Ingham (Professor Palliative Medicine, UNSW, Director Cunningham Centre for Palliative Care Sacred Heart Centre)

The workshop also included discussion about how the NSAP pilot will work for each service, perceived challenges and 'where to from here'. Feedback from the day was that the workshop was very productive and attendees appreciated the opportunity to network.

Regional training workshops

Following the initial pilot workshop, the NSAP team ran four regional training workshops in Perth, Melbourne, Brisbane and Sydney. Each service was invited to attend the training workshop in their PCOC zone. The aim of these workshops was to gain an understanding of what it means to be a pilot site and address potential issues and barriers that may arise during the pilot. As well as this services were encouraged to develop a 'community of practice' approach through which services support each other through the pilot.

During the workshops services gave an overview of their service and why they wanted to participate in NSAP pilot. This allowed everyone to get an understanding of the varying types of palliative care services that exist in Australia, and how NSAP might work in each of them. The key reason many services gave for wanting to be a part of the NSAP pilot is the opportunity to contribute to a national quality improvement program specifically for palliative care services, and to get an understanding of how their service measures against the national palliative care Standards.

The major barriers that were discussed at the workshops were getting ethics approval and forming a multi-disciplinary team. A variety of strategies and opportunities were brainstormed as to how to overcome these barriers, and suggestions were shared between the group.

All services felt that this was a fantastic opportunity to discuss some of their questions and concerns and left feeling inspired and prepared to 'get going' with the work ahead.

Left to right (top to bottom): Bradley Greer (DoHA); Jane Ingham, Sue Hanson and Patsy Yates discuss the finer points of NSAP; Linda Hansen catches up with Donna Daniell; Networking over lunch; Receiving resources for the day; Sue Hanson and Donna Daniell have a laugh.

National Quality Forum report

Palliative Care Australia (PCA) hosted a series of National Quality Forums between March and July 2008. These forums were held in each state and territory and were titled "*Working Together to Improve Quality in Palliative Care*". Over 200 participants attended the forums in Melbourne, Geelong, Sydney, Adelaide, Darwin, Hobart, Perth, Canberra and Brisbane.

The Forums provided an opportunity for both information sharing and feedback. Sessions included gaining a perspective on the policy and service development initiatives to support quality improvement in each state, an overview of projects and initiatives being undertaken and presentations from both the National Standards Assessment Program (NSAP) and the Palliative Care Outcomes Collaborative (PCOC) regarding their role in supporting quality improvement at a state and local level.

Issues and challenges identified by participants

A number of issues and challenges were identified by participants through some quite spirited debate and discussion. There was a great deal of consistency in the issues and challenges raised at each meeting. In general key issues impacting on quality improvement activities related to definitional issues, service models, data quality and data collection and reporting burden. These insights were incorporated into the early planning and development of the NSAP. Key issues identified in these areas were:

- A significant number of quality projects are currently being undertaken around Australia but it is difficult to tap into what is being done, to find out lessons learnt, share opportunities, etc.

- The difficulty defining what palliative care is and what a palliative care service is was acknowledged. Tensions between early referral and needs-based models were discussed.

- There is a need for a common understanding and agreement about language used in palliative care. Multiple terms have now come into contemporary usage and it is no longer clear that there is a shared meaning for all terms. Use of terms such as end of life and palliative approach are most troublesome. Issues related to continuity of care and system structure were raised.

- Participants were concerned that structural and philosophical issues may hamper the capacity of palliative care services to deal with the large numbers of people with chronic and complex care needs – it was suggested that a mind shift was needed if access to high quality care at the end of life was to become a reality for all.

- It was recognised that there is a need for consistency in the use of referral triggers to and from specialist palliative care services.

- There is a need to construct evidence-based, and patient journey based clinical pathways that guide the collection of data. Risks associated with reverting to disease based pathways rather than patient focused approaches were raised.

- Data burden is perceived as a significant issue for services. Data burden relates to data collection and reporting. Services and clinicians report variable access to infrastructure and resources to support data collection and reporting. Multiple and poorly integrated demands on services to provide data contribute to the perception of data burn out. It was felt that there would be value in integrating various data and reporting systems, including the development of data linkage arrangements to reduce burden at clinical and service levels. It was acknowledged that this would require negotiation at jurisdictional level.

- Participants felt strongly that data should be fit for purpose – that is it should be meaningful for clinicians, service managers and policy makers so that it can drive quality improvement and help answer broader questions about quality.

- Data collection services need to take into account the differences in services, including those operated autonomously, for example by Aboriginal Health Services.

- There is a lack of consistency in the data currently being collected and data collection is fragmented.

Opportunities identified by participants

In addition to the identification and discussion of a number of challenges impacting on quality improvement efforts, participants also identified and discussed the opportunities that the NSAP provided in addressing some of the identified challenges. These were:

- NSAP will enable us to see how different models of palliative care work to deliver quality care.

- The benefit of a quality improvement process is that you can review your performance over time – benchmarking one's own performance is more likely to be of more value than comparing with other services.

- The Standards have already been used to help drive culture change, even if they are a bit cumbersome. The Standards are useful because they ask questions about where there is unmet need. They enable services to ask themselves where and how they can intervene to provide quality care.

- The Standards are useful for discussions with primary care providers to promote quality care.

- Constructing peer groups will allow us to share information and understand what common issues are and what issues are particular to a service. Services can then collaborate on solutions to common problems.

- NSAP and other related activities provide an opportunity to refine the language and definitions used by data collection agencies.

What should we do first?

Forum participants identified a significant number of complex and far reaching challenges and opportunities. All journeys start with a single step however and a number of key first steps were identified. These included:

- Getting a better understanding of what we are currently collecting, what we need to collect and what we can drop.

- Ensure we are getting maximum benefit from existing data before we develop new data sets.

- Provide some clarity around language, definitions and terminology.

- Examine infrastructure issues and develop an infrastructure plan to support more comprehensive data collection for the sector.

The challenges and opportunities identified through the National Quality Forums have been incorporated into the design and development of the National Standards Assessment Program and have provided direction for consultation and ongoing negotiations with state and commonwealth government representatives around issues regarding data collection and reporting in palliative care.

NSAP Q&A

Q: I'm not in the pilot but want to do NSAP.

A: Great! Unfortunately services won't be able to start NSAP until after the pilot is finished and any alterations are made to the resources. We anticipate the national roll-out of NSAP to commence in early 2009. Keep an eye out for more details on how to 'sign-up' in future editions of 'the Standards' newsletter.

Q: Will my service have to get ethics approval before participating in NSAP?

A: Not necessarily. We are finding it is mostly the use of the NSAP Patient Interview and/or the Family Evaluation of Palliative Care that requires ethics approval. If your service is not using these audit tools, or is using alternative audit tools (such as FamCare), you may not need to get ethics approval. Read through the information provided in the ethics package, which will be supplied following registration, and consult with your ethics committee if you are not sure.

If you do need to get ethics approval for the FEPC or Patient Interview Audit tools, it is still possible to begin the NSAP self-assessment process. Focus on the areas and Standards that do not require the audit tools or ethics approval, until your ethics approval has come through.

Q: How do I get the NSAP resources?

A: Services participating in the pilot have received hard copies of the NSAP resources for use during the pilot. Once the pilot is completed and any updates have been made, the resources will be made available electronically via the NSAP website. These resources are anticipated to be available from early 2009.

Q: What's this I hear about the NSAP website?

A: The NSAP team has developed a website especially for services participating in NSAP. **During the pilot, the website will only be accessible to pilot services** who have been issued with a login to access secure services on the website. Following the pilot, all services participating in NSAP will be able to access a website that will be developed based on the pilot sites' feedback and experience.

Services available on the website include:

- A discussion board for services to post messages about their experiences and issues

- The ability to see who else is currently online and participate in live 'chat' via the discussion board

- A user controlled table, which can be update to reflect service's characteristics

- Electronic copies of the NSAP resources as well as additional resources that may be useful

- A feedback section

Q: Will NSAP lock services into using particular tools or evidence sources?

A: No. Services won't be locked into using particular tools. The NSAP Guide provides services with a list of possible evidence sources, however this list isn't compulsory or necessarily exhaustive as services may have other evidence available to them.

Q: Will there be linkages between NSAP and EQuIP 4?

A: Yes - ACHS have already published a document that maps the linkages between the 4th Edition Palliative Care Standards and EQuIP 4 and this is available to members free on their website. Services can use the evidence gathered for NSAP for EQuIP 4, and where a service meets the relevant palliative care Standard, they will also meet the EQuIP 4 standards/criteria to the extent mapped by ACHS.

Resources

The NSAP team has developed a series of resources to assist services in conducting their self-assessment. These include:

- Multi-Disciplinary Self-Assessment Workbook

- NSAP Documentation audit tool

- NSAP Patient Interview audit tool

- NSAP Family Evaluation of Palliative Care (FEPC) audit tool

- Modified postal version of the FEPC audit tool

- NSAP Pilot Guide

- NSAP Pilot website

Pilot participants received hard copies of each of these tools to use during the pilot and will provide feedback to the NSAP team on the useability and usefulness of these tools. The NSAP national team will then use this feedback to update the resources prior to national roll-out in early 2009.

At this stage resources are not available publicly but the finalised resources will be made available electronically via the website following the conclusion of the pilot.
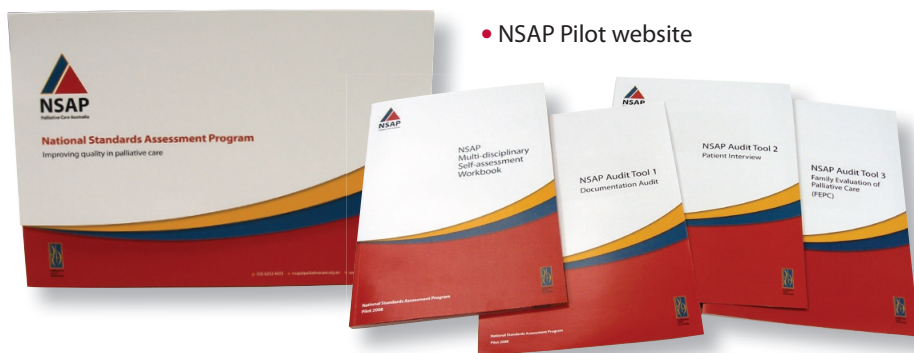
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