

DP 1335 / 07-11

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Our ref: MB/EH/0486/10
Your ref:

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20 July 2010

Dear Mark

During Questions on 23 June you raised an issue relating to palliative care services, and asked specifically about the informal review that Viv Sugar was to undertake on the progressive work of the Palliative Care Implementation Board.

I can confirm that Viv Sugar has reviewed the Board's work. There were no terms of reference for this piece of work and no written report was produced, as it was carried out on an informal basis. Viv ensured that the work being taken forward by the Implementation Board was in line with her Report's recommendations and she was content that the Board fully understood the requirements set out in that Report.

Viv has confirmed subsequently, to the Palliative Care Implementation Board, that she is pleased with the progress made and the direction of travel.

I am happy to enclose a Report, produced by Baroness Finlay which details the progress made generally by the Implementation Board in 2009-10 to improve palliative care services. This includes an update, informed by Viv Sugar, against each of the recommendations specified within the *Sugar Report*.

I am placing a copy of this letter and the attached Report in the Library.



**Report on Implementation of Palliative Care Strategy for Wales
Year 3**

Palliative care services funding 2010 to 2011

June 2010
Palliative Care Implementation Board

The Board

Professor Ilora Baroness Finlay (Prof of Palliative Medicine, Cardiff University) – Chair
Marion Andrews-Evans (senior nurse, Welsh Assembly Government),
Dr Helen Herbert (GP Aberaeron, immediate past Chair of RCGP Wales),
Viv Cooper (Clinical nurse specialist, Velindre hospital)
Alun Davies (Chief Executive St David’s Llandudno, a voluntary sector hospice)
Bernadine Rees (Health Board executive officer for Community services, Hywel Dda),
Gillian Evans (Patient – North Wales).
Dr Andrew Fowell (Consultant in Palliative Medicine, Gwynedd) – 2009. Vice Chair

Secondees to support the work of the Board:

Veronica Snow (Specialist nurse, Powys and SW Wales cancer network)
Lisa Miller (Manager, Velindre Hospital – on part time basis).

Abbreviations used in this report

SPC – specialist palliative care
SPCT – specialist palliative care team
GP – general practitioner
CNS – clinical nurse specialist
HIW – Health Inspectorate Wales
CSSIW – Care and Social Services Inspectorate Wales
WAG – Welsh Assembly Government
DNACPR – Do not attempt cardio-pulmonary resuscitation

Strategy Implementation Progress

The focus of the Implementation Board has been and continues to be to achieve the recommendations outlined within the Palliative Care Planning Group Report (2008) chaired by Viv Sugar. Additional work has been undertaken to build on the principles outlined in this report in the light of the new direction in NHS Wales and in patient expectation. In particular, the development of direct patient feedback has influenced service development, through the iWantGreatCare programme and, more recently, through Dying Well Matters.

The work of the Implementation Board has remained underpinned by the core principles that:

- Good end of life and palliative care should be available universally across Wales, irrespective of age, diagnosis, area of residence, gender, race or creed.
- Fairness of service provision is fundamental to raising the standards of end-of-life care. This needs to be achieved without jeopardising evaluated evidence-based service developments by the leading specialist palliative care service providers in Wales.
- Close integration of services in an area, whether from NHS or third sector providers, is essential for high standards in care.

Decision making has been underpinned by:

- The funding formula for specialist palliative care services, developed in an endeavour to ensure a minimum level of specialist service across Wales, has continued to have face validity. This has been tested by also looking at services outside Wales; the formula has held good.
- The voluntary sector providers have continued to receive funding from the LHBs; all now have secured contracts to provide stability. One Wales funding provides additionality to this LHB funding, not substitution.
- Funding agreements between LHBs and their local providers should set clear criteria against which progress can be monitored. Model funding agreements were made available to LHBs during 2009.

This report addresses the most recent progress, building on work undertaken during 2008-10.

Some key changes, set as objectives by the 'Sugar report', are:

7-day working by clinical nurse specialists and 24/7 consultant advice established

Transitional care lead for Wales is in post

Increase in consultant posts across Wales

Training of CNS to higher degree competencies in palliative care

Increase in allied health care professions posts

There is at least one designated paediatrician in each HB with a special interest in palliative care

GP education programme in palliative care has been developed and rolled out across Wales

Every nursing home has a named CNS for advice and training

Integrated care pathway has been revised and piloted, prior to being launched in June 2010

A unified all-Wales DNACPR form has been developed through the Ambulance service

2009-2010 Overview

Table 1 outlines the progress as of April 2010 against the strategy outlined in the Sugar report.

Table 1
Progress against Recommendations
Short Term Outcomes : Expected within Year One (2008-2009)
<p>Most of the short term outcomes were achieved early in the first term of the Board.</p> <ul style="list-style-type: none">• The Implementation Board and the All Wales Clinical Network Groups (adult and children) are now well established to support the service developments required.• Consultant numbers have been established for adult services, paediatric services and transitional care (see table 2 for full details of establishment). Over 140 consultant sessions in palliative medicine have been established across Wales to fill service gaps, plus two SpR training posts, other medical support sessions and part-time staff grade cover in W Wales. Stability and governance has been provided by ensuring all consultants are NHS/ University employed.• CNS numbers have also been benchmarked to inform funding. Funding has been prioritised to address areas of most need.• Transitional Care Lead appointed in Jan 2010.• Paediatric medical sessions in each LHB area, and some nursing posts, are funded to meet prioritised need; staff education and training is integrated into the development. Additional paediatric palliative medicine sessions have been funded in Swansea to serve West Wales• Increase in Allied Health Professional Posts (Cwm Taf, Conwy/Denbigh) Also, a national lead physiotherapist (due to be appointed in May 2010 in Cardiff & Vale) as an All Wales resource to fellow professionals for the particular problems of teenagers with advanced muscular dystrophy.• Increased investment to increase CNS capacity & Agenda for Change costs for 7/7 working• £2 million funding allocation ring fenced for Third Sector allocated using the Core service model funding formula was exceeded in 2009.• Continuing Healthcare Funding expenditure on palliative care has been quantified in one LHB area. Work to evaluate this expenditure across Wales is ongoing with colleagues in WAG.• Standard clinical guidance and All Wales guidelines for palliative care have been agreed by all the consultants in Wales and are available on the 'Palliative Care in Wales' website http://wales.pallcare.info . This includes a dose conversion tool to decrease the risk of error when rationalising prescribing for a patient on a variety of opioids.• Draft Standards have been developed with Health Inspectorate Wales to be used as Palliative Care quality markers within the generic Healthcare Standards. Consultation planned June 2010.• Work on equipment has been difficult because the processes vary in different LHBs. Delays in home adaptations remain a problem for patients with neurological disease; this will be part of the Board's work in 2010.

Medium Term Outcomes : Expected within Years One-Three
All of the medium term goals have been achieved , or will be achieved by December 2010
<p>Establish a 24 hour service advice line across the whole of Wales for both adult and paediatric services using staff with Palliative Care experience and who have access to an on call consultant:</p> <ul style="list-style-type: none"> • All consultants in adult palliative medicine participate in a 24/7 on-call rota to provide advice to other health care professionals in Wales. • The network of paediatricians with a special interest in palliative care will provide advice through a paediatric rota. • 24 hour contact numbers in place in each Local Health Board area. Helpline to support these arrangements agreed with CALL using 0300 number. • CALL expected to be used as last resort due to work undertaken within each locality.
<p>Produce a separate circular for adult Palliative Care commissioning guidance:</p> <ul style="list-style-type: none"> • Model funding agreement developed in 2009 and available for LHBs. Meetings established with the executive leads for community services to ensure consistency in approach.
<p>All Wales Training and Education Programmes:</p> <p>Primary care:</p> <ul style="list-style-type: none"> • A short course for general practitioners has been developed and rolled out; to date over 50 GPs have taken part in the course, which has evaluated well. • Macmillan Cancer Care has funded bursaries for GPs to attend the short course. • The District nursing palliative care course in Cardiff & the Vale is being adapted for roll out across Wales. <p>Secondary care and community hospitals</p> <ul style="list-style-type: none"> • E-learning for Health palliative care modules for all health care workers at all grades will be launched in Wales June 2010 <p>Nursing and residential Care homes</p> <ul style="list-style-type: none"> • Each nursing and residential care home has a named CNS responsible for linking with the nursing home and providing a resource, particularly around the use of the end of life care pathway to plan care for those who are dying in nursing homes. • The Gold standards framework for nursing homes has been explored with the group in England who developed the programme; evaluation is being sought prior to a final decision being made.
<p>Nominate a single regulating authority for inspection of all core services and develop inspection regimes for all clinical governance systems with peer review against agreed standards:</p> <ul style="list-style-type: none"> • Incorporated with Standards work with CSCG, HIW and CSSIW.
<p>Develop the current IT systems for adult Palliative Care and establish an IT system for children's Palliative Care:</p> <ul style="list-style-type: none"> • Roll out of CANISC in statutory sector expected June 2010 • Roll out of CANISC in Third sector expected October 2010

- A third sector CEO (Nightingale House Wrexham) has been designated as the CANISC third sector 'Champion'
- The roll out to children's services should follow full adult service implementation, although this is threatened by the delays in CaNISC to date
- Investment in data-entry clerks from 'One Wales' fund for all providers within 2009/10 budget

Conduct further work to identify the specific needs of adolescents and young adults and nominate a member of the Palliative Care network to liaise with all networks on transition issues:

- Palliative care lead for transitional care took up post January 2010 (see above).
- A consultant post based in Llandough hospital since Nov 2009 is now working with the respiratory clinics there, allowing the consultant based in UHW to focus on neurology and the UHW hospital palliative care support team.

Improved Data Collection on patient numbers and conditions to inform commissioning and develop a register of need:

- CaNISC installation will achieve this target

Access to information for patients, families and carers, including a directory of services:

- Information will be available through CALL and individual teams.
- Further consideration is required regarding 'Best Practice' on the format and sustainability of providing 'real time' information on an All-Wales basis. Each palliative care service has been encouraged to provide leaflets and cards with information for patients and carers.
- The website <http://wales.pallcare.info> is not password protected. It provides information about all aspects of palliative care in Wales and is freely available to professionals and to others. Its first section is for patients and carers to locate, and if they wish to review, their local specialist palliative care team.
- iWantGreatCare is a patient evaluation system that has been rolled out across Wales. Each patient seen by a palliative care team is invited to complete a simple evaluation of the service against 9 key indicators and free text comment is also invited.
- Dying Well Matters is an initiative inviting comments of what went well and what needs to be improved from those experiencing end of life care across Wales in all services, not only specialist palliative care. Themes from the narratives directly inform strategic decisions.

Expansion of services to non-cancer patients:

- Meetings have been held with representatives of the cardiac network, geriatric medicine and the neurological alliance. Cardiac Nurses across Wales have been specifically tasked with establishing links with their local Palliative Care Teams.
- Cardiac Guidelines for the Referral to Specialist Palliative Care have been agreed and are now in use throughout Wales
- Process mapping of all Non Cancer CNS's is being undertaken. This will allow all Specialist Palliative Care teams are to have a register of contacts of Non Cancer Palliative Care CNS's in their catchment areas.
- Discussions are taking place with Alzheimer's Society to identify the training needs of Palliative Care teams.
- One Day conference 'Power of Partnership' held with National Council Palliative Care to explore End of Life Care needs for patients with Dementia and related disorders May 2010

- Presentations on the work of the Implementation Board to the All Wales Paediatric Specialist Palliative Care Nurses and the South West Wales Cardiac Network meeting May 2010

Deaths in transit:

- A DNACPR form, developed with the Ambulance service and WAG, has been agreed at an All Wales level. It has been disseminated to all Trusts and GPs across Wales and can be downloaded from 'Palliative care matters in Wales' <http://wales.pallcare.info> website

1. Working of the Board

Funding Allocation 2009/2010

One Wales funding (totalling £4 million) was allocated in 2009 in line with the formula outlined in the initial report. Following discussion with all providers, the Funding Agreements were signed off with both statutory and third sector organisations. Meetings to discuss the contracts took place with all the individual hospices. A continued dialogue between the Board and all palliative care providers took place on a regular basis in and around Wales during 2009, with a series of meetings with different services.

Board Meetings

The Board meet quarterly at agreed regional venues in Wales. Public meetings were held during 2009 where the work of the Board was presented and public engagement was sought on the changes introduced. These took place:

- September 15th 2009: Prince Philip Hospital, Llanelli
- November 12th 2009: Wrexham Maelor Hospital, Wrexham

Underspend

By January 2010 an underspend on the funding Allocation for 2009/10 was identified. Working with each Health Board Clinical Lead, a virement of the funding was achieved to support service priorities. £50,000 was returned to WAG. In some instances funding previously allocated to the statutory sector was transferred to third sector providers.

Third Sector virement funding beneficiaries were:

- Paul Sartori Foundation, Pembrokeshire.
- Nightingale House Hospice, Wrexham.
- St David's Hospice, Llandudno.
- St Kentigern Hospice, St Asaph.

Four Nations Meeting

A four Nations End of Life Care meeting was held in December 2009 in Edinburgh. The work of the Board to date in Wales was shared with colleagues from England, Scotland and Northern Ireland. There was a particular interest in the 'Funding Formula'. Data from parts of England is being used to establish face validity of the formula used to plan services.

Action:

A further Four Nations meeting is planned for 13th July 2010 in London.

Awareness Events for Assembly Members, Welsh MPs & Peers

The strategy implementation has been presented to an open meeting for all AMs, at the Cross Party Neurosciences Group in the National Assembly of Wales and, at a Parliamentary meeting to Welsh MPs and Peers. The MPs and Peers expressed satisfaction with the work of the Board, particularly noting the stress on fairness of access and 7 day service provision; they also were reassured that cross border issues had been taken into account as the services developed.

Action:

A further update is planned for Assembly Members through the Cross Party Hospice Group and in Parliament for Welsh MPs through the All Party Parliamentary Group on Hospice and Palliative Care

Third sector

Partnership Working

The Board is committed to collaboration to achieve effective partnership working across all sectors. During the year regular and productive dialogue has taken place with major voluntary organisations and interested groups: Independent Hospices Cymru, Marie Curie and Macmillan Cancer Support, Cancer Alliance Wales, National Council Palliative Care (NCPC) and Dignity in Care (Wales).

Progress to date has been:

- i. Planned meetings with the Chair of the Independent Hospices (IHC) in Wales, discussing issues as they arise.
- ii. Discussion with Marie Curie to explore best practice and innovative ways of supporting patients at home during the End of Life phase.
- iii. Regular meetings with Macmillan Cancer Support, resulting in funding directed at improving education in Primary Care.
- iv. Welsh Conferences during May and June 2010 jointly with NCPC and National Alzheimer's Society on End of Life Care in Dementia.
- v. Board representation on the panel of the Dignity in Care Events in Wales during April 2010.

The One Wales funding, ring fenced at £2 million for the voluntary sector, was increased above this minimum to £2,077,500 in 2009-10 and, in addition, capital funding support was been received by several independent hospices in Wales. All voluntary sector hospices have secured funding agreements with their LHB; all but one have established 3-year rolling contracts.

In 2010-11, One Wales the value of financial support the voluntary sector rose to £2,501,560.

1 Service planning, monitoring and reporting

The Implementation Board has established clear links with all the specialist palliative care providers.

As the new Local Health Boards have come into existence in Wales, links have been established with all the Directors of Primary and Community Services, particularly to share information over funding agreements and continuing care arrangements.

The three regional groups of the Cancer Services Coordinating Group (CSCG) had palliative care advisory groups. Following discussion with Dr Jane Hansen, it was agreed that the implementation board would take over the strategic planning role and link with the seven health boards. The

standard-setting role that the palliative care group have had centrally within CSCG would continue and would link with the work undertaken in conjunction with Health Inspectorate Wales.

1.1 Clinical Network Establishment

1.1.1 Palliative Care Implementation Groups in each Health Board – P-CIG

The Palliative Care Implementation Clinical Network Group (P-CIG) has been established to bring together the medical, nursing and management palliative care leads in each Local Health Board; to date, few LHBs have been able to identify a lead GP for palliative care. The group reports through the chair to the Implementation Board; it meets on a quarterly basis.

Its role is to address common issues across Wales and find solutions. The group is tasked with:

- Cascading out key information from the Implementation Board
- Feeding back strategic information to the Board to bring local services together
- Establishing commonality of working practices
- Establishing pooled rotas of clinical staff and staff rotation
- Undertaking Health Board-wide audits and quality control
- Monitoring finances, particularly of services with multiple funding streams (e.g. LHB core agreements, Wanless funding, Continuing Healthcare funding)

The Clinical group have been able to support the achievement of:

- 24/7 On Call Rota for Palliative Medicine Advice
- Introduction of 7/7 working for CNS's across Wales
- Integrated working within Health Boards by all provider organisations
- Transfer of medical and nursing contracts to NHS providers were appropriate to support Clinical Governance.
- Identifying service gaps and prioritisation for future funding.
- Identification of a named nurse (CNS) contact for all Nursing homes in each Health Board
- Roll out of All Wales Integrated Care pathway for the last days of life
- Review All Wales DNACPR processes
- Assess coding for consistency of PACT data to continue

Action:

This pan-Wales group is proving strategically important. It will be important to maintain the momentum of work in progress.

1.2 Keeping palliative care on the new Health Boards agenda

Palliative Care responsibility sits within the Primary Care Directorate in most Health Boards. The Chair of the Implementation Board meets the Health Boards' Directors of Primary Care at their monthly meetings on a regular basis. The purpose of the meetings is to:

- Update the Directors on the work of the Implementation Board
- Share locality issues as they arise
- Seek the advice of the Directors regarding service reconfiguration
- Share and agree the role of the Funding Formula and Service Specification on future service planning.
- Ensure close working between the Implementation Board and the Primary Care Directorates

Actions:

Continue to work collaboratively with the Primary Care Directors.

Work with the LHBs to adopt consistent service specifications and terms in funding agreements for both general and specialist palliative care provision by NHS and voluntary sector providers.

The Board previously recommended that LHB papers should be audited for evidence of palliative care as an agenda item. This will be undertaken over 2010-11.

1.3 CaNISC palliative care module development

The dataset for CaNISC has developed more slowly than planned, in part due to the requirements of the Assembly's Welsh Information Governance and Standards Board (WIGSB) procedures that have required information to be repeatedly resubmitted before further progress can be made. The core dataset has been defined and agreed by clinicians over a year ago; it has now entered systems testing and will then proceed to user acceptance testing.

All consultants have been issued with laptops with the intention that they can access CaNISC out of hours using the VPN token system; this will allow access to patients' case notes for those patients registered on CaNISC. The roll out of the system to the voluntary sector has also proceeded and a Voluntary sector provider – Nightingale House – has taken on the role of champion for the voluntary sector. Training of non-statutory sector users is 83% complete; all statutory specialist palliative care organisations are connected and training is complete.

Each Specialist palliative care team has been provided with dedicated funding for a data-entry clerk to decrease the administrative burden on clinical staff and ensure accuracy of data entry.

A full time project manager has been overseeing the development of CaNISC; an IT specialist and consultant clinical advice has been seconded to the project through 2010-11. The programmed activity to train staff in data input has continued.

Further delays relate to delay in installing connections in the non-statutory hospices and the delays caused by repeated submissions through WIGSB are non-recoverable time. There is concern that the way CaNISC is to be supported across all its components in the long term has not been agreed. Cost proposals were brought to the CaNISC Senior Management Board and the Implementation Board in 2009; these were felt to represent inappropriate high costs for which there is no budget provision; as such this will seriously threaten the viability of the palliative care module of CaNISC.

Action:

Completion of the palliative care dataset module had been targeted for July 2009. The new date for the CaNISC palliative care module to be fully functional is October 2010.

Negotiation of the infrastructure support costs for the long term is urgent.

1.4 In patient beds

There has been no evidence of a need to expand specialist palliative care inpatient beds. In Powys, the transfer of patients from Secondary Care directly to Community Hospitals may have reduced the number of patients being given the choice to die at home. A requirement for a plan of care detailing actions to support preferred place of care is required to audit place of death in relation to preferred place of care.

Those areas without dedicated inpatient beds have developed various hospice at home models (Gwynedd, Paul Sartori, St David's Foundation Newport, Wrexham/Flintshire NHS team)

Respite bed provision

The Sugar report highlighted the need for respite provision. Three distinct projects have been funded to develop respite care on a formal planned basis. These are 3 beds in St Anne's Malpas, one bed in St David's Llandudno and one to three beds in Shalom as a phased development.

In addition to these developments, the Board, through the Chair, has had discussions with the MS Society about the respite needs of those with MS; a clear call for adapted holiday accommodation has come from patients across the UK including form focus groups held in Wales.

Action:

Better activity data analysis is anticipated through CaNISC. The respite beds will be evaluated in late 2010

The Board will explore potential for suitable holiday/ respite accommodation with the Welsh Tourist Board and Social Services

1.5 *DNACPR (do not attempt cardio-pulmonary resuscitation) advance statements*

A policy on DNACPR has been developed with the Ambulance Trust and is being rolled out widely with a leaflet specifically designed to support ambulance crew.

Action:

A major review of the policy for dealing with transport requests is required, including exploring the use of a central booking point to fast track patients requiring specialist palliative care

1.6 *Day care services*

Day care was not included in the original Sugar report. The role of Day care remains unclear.

Action:

Joint working with stakeholders is needed to further evaluate the role of day care.

Drug availability for patients at home.

The different systems in the new Health Boards mean that arrangements of out of hours drugs in the community vary. A meeting of the Chief Pharmacist, the Board Chair and the palliative care specialist pharmacist in ABMU has begun to explore the complexities involved.

2 The patient experience

2.1 *Independent evaluation of services*

The implementation board feel it is essential that the patient experience is used to:

- inform strategic development
- provide quality assurance as part of the triangulation of environment, patient experience and governance in monitoring standards
- identify good practice and encourage further development
- identify problem areas and feedback directly to improve services

To this end, two programmes have been created: iWantGreatCare and Dying Well Matters.

2.1.1 *iWantGreatCare*

Each patient seen by specialist palliative care is given a simple feedback form which asks nine questions against each of which the respondent (patient or carer) can rate their response from 0 to 10. There is also free text box for comments. The questions relate to:

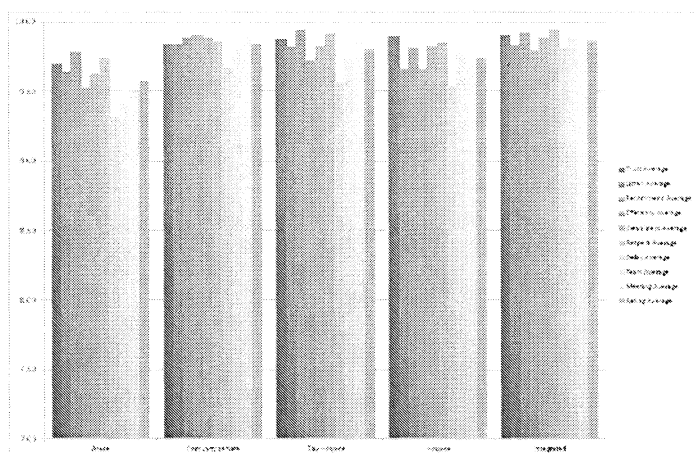
1. Do you trust the staff?
2. Do the staff listen to you?
3. Would you recommend the staff?
4. Are you looked after efficiently?
5. How clean is the environment where you are treated?
6. Are you treated with dignity and respect?
7. Are you looked after promptly?
8. How well do staff address your fears?
9. How well do staff meet your needs?

The questionnaire was piloted in ABMU in September 2009 and subsequently rolled out across all the specialist palliative care services. Patient returns have been received from 40 of the 48 specialist palliative care services and has shown very high levels of patient satisfaction. The questions have been shown to be discriminatory with a range of numerical responses that correspond to the free text given. The scores range from zero to 10 in several domains, with an overall average over 9.5 and a median of 10; the majority of scores were 10 / 10 in all domains. Very slightly lower scores are seen in the areas of services responding promptly to patient need and staff addressing patient fears, but it is not clear as yet whether these will emerge as significant areas to be addressed. It was expected that scores above 7/10 would be satisfactory, so these high scores reflect excellence in care based on the reports of the patient experience.

Scores from NHS services are as high as those from voluntary sector services. Hospital support teams scores were expected to be significantly lower of the patients are often seen in a mixed environment and may find it difficult to disaggregate care from the specialist part of care team from other parts of their experience; however, the acute hospital support team scores are also very satisfactory.

Each specialist palliative care team now receives updates feedback monthly which allows the team to review the scores accorded to them and the free-text comments. Almost 700 feedback forms have been received. The average score for all services is 9.6/10 with 84% of feedback forms rating 10/10 in every domain.

Fig. 1. Comparative average rating scores by domain for each type of specialist palliative care team.



Although patients had the opportunity to complete evaluations online, none have used this facility to date. However, the website is being developed so that patients can see the ratings for services in Wales.

Feedback is now being given regularly to teams in a format that collates free text comments directly with individual domain ratings.

Action.

Maintain momentum, establish regular feedback to teams through the programme manager, and identify areas of change required locally and national through feedback

2.2 Dying Well Matters

As the majority of dying patients receive most of their care most of the time from services that are not specialist palliative care services, the implementation board felt it is important to receive feedback from across the whole health economy about things that went well and things that should have been done differently. Complaints to hospitals and community services in Wales often relate to end of life care.

As part of the '1000 Lives' project in Wales, patients' stories have been collected. This methodology is being used to encourage the relatives of patients (and possibly patients themselves if they are well enough to do so) to feedback on end of life care. Following the project's launch on 9th December 2009, a pan Wales publicity programme has been planned for May 2010. Despite relatively little publicity to date, several themes are emerging from the issues brought to the attention of the Board. These are:

- Delays in receiving adequate analgesia
- Poor management of constipation
- Inadequate communication of a poor prognosis, leaving families ill-prepared for the patient's death

- Poor communication from community services to hospital specialists when patients at home are deteriorating
- A risk-averse rather than risk-intelligent approach to patient management
- Defensiveness by some staff when patients or relatives question aspects of clinical management
- Teams unable to offer the full range of services required to support complex patients
- Inadequate monitoring of commissioned services

It would appear that most parts of NHS Wales and their third sector partners provide excellent patient focused end of life care, but the benefits of this are distorted by a few encounters with parts of the service that are not working well.

There is consideration being given to having regional user facilitators to support people who are ‘telling their stories’.

Action:

Themes needing rectification will inform review of the standards monitoring system, providing constructive information on which to shape future services. The Themes will also be shared with the Clinical Leads through the Palliative Care Implementation Group

The specific issues raised will be brought to the attention of the relevant parts of the services across NHS Wales.

Information on how to respond to Dying Well Matters is being distributed widely throughout Wales; Velindre is hosting the freepost address for these.

2.3 Central point of out-of-hours contact [*‘0800’ or an ‘easy’ number*]

The Community Advice and Listening Line (C.A.L.L) is a confidential mental health and bereavement helpline, is based in North Wales and provides a bilingual service using both the telephone and text messaging, available 24 hours a day, 7 days a week, making the service suitable for a dedicated palliative care call line.

While this model was being explored, the development of 7/7 working by CNS’s and the 24hr on call consultant rota required Health Boards to develop out of hours access lines for specialist palliative care. These numbers will now form the first point of contact, while the CALL number will provide a ‘failsafe’ safety net number in circumstances where all else fails or patients/ carers become anxious and are unable to receive adequate advice.

Each service will receive the card template to which they can add their own ‘logo’ and contact numbers. The CALL number will be printed on the bottom of the card for emergency use. A 0300 number has been allocated to this service. The card will also record the patient’s CaNISC number. To test the reliability of the model, each Health Board is now required to submit their Consultant ‘on call’ rotas along with the CNS 7 day working rota to CALL to ensure the CALL team have adequate information. A pilot run will take place shortly to test the robustness of the system.

3 Specialist palliative care teams

3.1 Consultant led services

Actions taken to date to rectify the shortfall in consultants are set out in Table 2; these are all NHS posts, ensuring stability and governance long term. To supply the vacancies arising through new posts and retirements, two SpR posts have been created: one in the community in SE Wales and one in North Wales.

Three rotas are in place to provide consultant advice to other health care professionals: North, West and SE Wales.

Table 2 Medical sessions created / altered since 2008

Main area of work	Clinical sessions	Funding source	Employer	Status
Betsi Cadwaladr University				
Gwynedd and Llandudno	10	One Wales	BCU	In planning
Conwy Denbigh – Ysbyty Glan Clwyd; St David’s hospice Llandudno; St Kentigern hospice	6+	One Wales	BCU	Allocated across 3 consultant posts
Powys				
North Powys – based from Severn hospice	6	One Wales	Velindre	Advertised
South Powys	4	One Wales	Velindre	In post Jan 2010
Hywel Dda				
Ysbyty Bronglais, Ceredigion community plus Machynlleth & Tywyn S Gwynedd	10	One Wales	Hywel Dda	Appointed Start Aug 2010
Shalom Hospice Assoc Specialist	4.5	One Wales	Hywel Dda	In post 2009
West Wales General	10	Hywel Dda	Hywel Dda	Advertised
Abertawe Bro Morgannwg University				
Neath hospital /community	10	One Wales	ABMU	In Planning
Swansea hospitals	10	ABMU	ABMU	Vacancy
Ty Olwen	6	ABMU	ABMU	Vacancy
Aneurin Bevan				
Gwent – Neville Hall hospital	6	One Wales	Velindre	In post 2009
St Anne’s Hospice	6	One Wales	Velindre	In post 2009
St David’s Foundation	6	One Wales	Velindre	In post 2009
Caerphilly Miners hospital & community	10	One Wales	Velindre	In Planning
Royal Gwent Hospital	8	AB / One Wales	AB	In Planning
CwmTaf				
N CwmTaf – Merthyr/ Hospice of Valleys	6 -> 10	CwmTaf/ One Wales	Cwm Taf	
Royal Glamorgan Hospital / Y Bwthyn Pontypridd	5 -> 10	CwmTaf / One Wales	Cwm Taf	Start July 2010
Increase medical support to Cwm Taf consultants	6.5	One Wales	Cwm Taf	August 09

Cardiff and Vale				
Holme Tower Marie Curie hospice and Cardiff/ Vale community	20	One Wales	Velindre	Posts moved into NHS
George Thomas Hospice Care	10	One Wales	Velindre	In post 2008
UHW and Velindre	6	One Wales	Velindre	Post previously Marie Curie funded in part
Llandough Hospital	10	One Wales	Velindre	Dec 2009
CaNISC lead & support to Board	6	One Wales	Velindre	Nov 2009
Training posts				
SpR post in community - SE Wales	10	One Wales	Velindre	In post Aug 09
SpR post in N Wales	10	One Wales	Betsi Cadwaladr	In post July 2009
LAT training under clause 14	10 for 1 yr	One Wales	Velindre	Completed
TOTAL sessions funded by One Wales	200			

3.2 Out of hours (7-day) working by Clinical Nurse Specialists

In response to the Ministerial letter of July 2009, all bar one of the CNS palliative teams, began 7 day working by April 2010. The first area to pilot 7 day working was ABMU in the Bridgend area in June 2009. The outstanding area has been NE Wales (Betsi Cadwaladr), which commences 7 day working in June 2010.

An external review of the progress on 7 day working was commissioned from Chris Lloyd Richards during 2009/10, a recently retired specialist nurse with extensive experience of working in palliative care in SE Wales and with in-depth knowledge of the both the statutory and third sectors. She has interviewed all teams in Wales, recorded progress within each team on implementing the change and been an observer during weekend shifts in all areas. Her report forms the basis for a further review in a year's time. A summary of the report is attached (appendix 2).

Some teams have adopted novel rota solutions to meet patient need and the review by Mrs Lloyd Richards highlighted areas of good practice that are being shared with other teams.

Action:

7-day working is a core criterion in all funding agreements for specialist palliative care services. All new / replacement posts must incorporate 7-day working in the job description.

The review will be repeated in late 2010 early 2011, to assess the impact 7 day working has had on patient care, identify areas of vulnerability in the service, including any ongoing resistance to change, and to highlight good practice for dissemination.

3.3 Specialist nurse training

Eight nurses from around Wales have now enrolled for the M level courses in palliative care at Cardiff University. Amongst those who have already completed their first or second year, their clinical teams have found a marked increase in competence, skills and confidence, to the benefit of patients and their families.

Action:

Plans are on target for all CNSs in Wales to have completed or be in the process of completing a higher specialist training programme at M-level in Palliative care by 2011.

Those in paediatric palliative care have been specifically targeted and a cohort begins training in Sept 2010.

Data on workforce training should be updated in each LHB.

Senior nurses in non-cancer disciplines will also need encouragement to ensure that competencies required in the 'Post Registration Career Framework for Nurses in Wales' are met. Consideration should be given to establishing 7 day working amongst CNSs in other fields (e.g. neurology, cardiac) but this falls outside the remit of the Implementation Board.

3.4 Allied health care professionals

Specific funding has been allocated to Betsi Cadwaladr and Cwm Taf LHBs. In addition, Nightingale House and Holme Tower Marie Curie Hospice have experience of non-invasive ventilation in the hospice setting, so funding of 0.5 WTE specialist physiotherapy and 0.5 WTE CNS has been allocated to each hospice.

The funding for a respiratory team based from Cardiff and the Vale includes physiotherapy time.

3.5 Research developments

There is now a Wales wide research network in palliative care established, with 4 clear themes:

- The patient experience
- Thrombosis
- Cachexia and rehabilitation
- End of life study methodology

This is based from and supported by Wales Cancer Trials Unit There are collaborative links with Bristol, Oxford and Marie Curie, and the UK NCRI groups relevant to palliative care across primary and secondary care, involving both physical and psychological aspects of end stage disease. Health economics expertise is being integrated to the work streams.

There also close working with National Institute of Social care and health research, who have supported a palliative care research facilitator in Wales, and with the Welsh Health Economics Support Service and the Wales Equality and Diversity in Health and Social Care Research and Support Service (WEDHS).

These research developments are important to evaluate the basis of interventions, drive up standards of clinical care and to provide and evaluate proposed solutions to problems encountered by patients with advancing disease.

The portfolio of research is expanding; until last year, only 5 patients had been recruited into NCRI approved palliative care studies in Wales from 2006-09; in the first seven months of the new recruitment process 43 patients have already been recruited and by summer 2010 there will be 4 studies running concurrently in SE Wales..

These are:

Acronym	Study	Recruitment to date
EPAT	A multi-centre cluster randomised controlled trial of the institutionalisation of cancer pain assessment as a 5th vital sign (EPAT©) versus current best standard care	46 patients
SCORAD	A randomised feasibility study of single fraction radiotherapy compared to multi-fraction radiotherapy in patients with metastatic spinal cord compression	4 patients
QUARTZ	A phase III multi-centre randomised controlled trial to assess whether optimal supportive care alone (including dexamethasone) is as effective as optimal supportive care (including dexamethasone) plus whole brain radiotherapy in the treatment of patients with inoperable brain metastases from non-small cell lung cancer.	1 patient
Pregabalin	A double-blind randomised controlled trial of pregabalin versus placebo in conjunction with palliative radiotherapy for malignant bone pain	

The Annual Academic Palliative Care meeting in Wales at Gregynog remained oversubscribed again last year, with presentations of original work for specialist palliative care providers from both voluntary and statutory sectors.

Action:

The small amount of funding last year is providing road shows around Wales to ensure all clinical teams are research aware and promote access for patients to the research process.

It is important that all those organisations providing specialist palliative care services recognise the importance of research to drive best practice and establish the evidence base relevant to Wales. Therefore funding Agreements this year will include a requirement of active participation in palliative care research in Wales as directed through the Wales Clinical Trials Network.

3.6 Continuing care review

Differences in continuing care funding administration became evident across Wales. Meetings with the WAG lead for the review of continuing care, and before that with her predecessor, have informed discussions with the Health Board senior managers for community care.

The Board hopes to be able to input into the current review of continuing care funding across Wales.

4 Primary care development

A series of meetings, led by the Royal College of General Practitioners with GPC Wales have focused on a Welsh Directly Enhanced Service specification for GPs. Funding for this is being sought from the Primary Care Directorate in WAG. .

4.1 Education and training

4.1.1 GP education

The education programme for GPs has run in N, W and SE Wales, with good evaluations from those attending. Macmillan scholarships are available for GPs to participate the course. Publicity is difficult because GPs are so inundated with literature that the 4 mail shots appear to have gone unnoticed in some surgeries.

Action:

Further targeted advertising for the course.

4.1.2 District nurse education

The district nursing course in palliative care from Cardiff and Vale is being adapted for other parts of Wales.

4.2 Gold standards framework

A Wales 'GSF' 'Going for Gold' Conference was held in Cardiff May 11th 2010

Three GSF practice facilitators are each working with five practices in their Health Board area to introduce the GSF model.

4.3 Nursing homes / EMI homes

Each Health Board nursing lead on P-CIG is tasked with ensuring there is a named community specialist palliative care nurse for each nursing home, residential home, elderly mentally infirm home and residential places of custody.

The board has secured agreement for the e-learning for health in palliative care (aimed at all social and healthcare personnel) to be available across Wales. It will be introduced into Nursing homes by the CNSs.

4.4 e-learning for Healthcare

The Department of Health developed modules aimed at staff of every grade, to empower them to provide better care for patients. The modules include several on aspects of communication with patients. This has now been made available to staff in Wales at no charge and is to be rolled out over 2010-11.

5 Standards

5.1 Clinical standards

The Welsh Cancer Standards for specialist palliative care and generic palliative care (as included in the cancer site-specific standards) are due for revision. The standards have informed the database development on CaNISC, so that the verification process will draw on data that is routinely collected and thereby avoid duplication of work. Cancer Services Co-ordinating Group standards for palliative care set in 2005 have been erratically implemented in many parts of Wales. Some of the standards no longer reflect efficient working of teams and need revision to reflect the changing work-pattern as services are increasingly integrated.

Action:

The palliative care Implementation Board standards for generalist services and for specialist services have been defined but now need to be incorporated into assessment tools.

5.2 Inspection standards used by HIW and CSSIW

Following a joint meeting of stakeholders on May 1st 2009, Health Inspectorate Wales has reviewed its standards for inspection of hospices to improve the sensitivity of criteria to assess quality of care provision. These standards are also being adapted for general nursing and residential home beds.

The standards currently under development will sit under the recently revised generic Healthcare Standards as palliative care quality markers. They will evaluate a range of care settings including Day Hospice care.

Action:

The next step is to establish peer review of services across Wales, with coordination between HIW/CSSIW and CSCG. This can then inform next year's round of CSCG assessments. There is a need to ensure that children and teenagers specialist palliative care services are able to provide integrated care to those with complex medical needs, particularly when dying.

5.3 Service specifications and funding agreements

Model funding agreements were produced by the implementation board working group last year to cover general palliative care provision by voluntary sector and specialist palliative care services.

Action:

Adoption of the funding agreements to support service specifications needs to be co-ordinated with the community funding lead for each LHB.

The outline agreements can be developed to be applicable to Paediatric Palliative Care services.

5.4 Care in the last days of life

Use of the all Wales integrated care documentation for care at the end of life has increased across Wales in the past year. Audit has shown that its use improves care of patients and their families.

The documentation has been revised and simplified for routine use in the light of feedback. It includes a prompt to consider organ donation.

Action:

Modification for use in intensive care and emergency department sudden death is in progress.

6. Services for patients with other (non-cancer) diagnoses

All specialist palliative care providers were set an advisory target to increase their availability to those with a non-cancer diagnosis. The overall target set for 2009-10 of 10% non-cancer patients was not met.

The implementation board, through P-CIG, has worked to promote links between specialist palliative care CNSs and other CNSs. The board has also met directly with different specialty groups.

Respite Beds

The respite beds at Saint Anne's Hospice, Gwent (three beds), St David's Hospice, Llandudno (one bed) and Shalom, Pembrokeshire (in development) are targeted to provide non-cancer services.

Discussion with the MS society has suggested that patients seeking respite, particularly earlier in their disease, would prefer to be cared for in a non-hospice environment. However, discussion with the Motor Neurone Disease Association and a review of their Parliamentary enquiry suggests that these patients need to know that they are safe in an area with expertise available to deal with crises that may occur.

6.1 *Neurological disorders*

Several meetings have been held with the Neurological Alliance. The funding for many specialist nurses posts in neurology has come from different disease related charities; this has tended to promote isolated working by disease specialty.

A programme to evaluate care of patients with multiple sclerosis is being developed between the Wales clinical trials unit and the Cicely Saunders Institute at King's College, London.

Action:

Seven day working and cross covering could occur with the specialist health care teams and could supplement provision across Wales.

As in last year's report, we again suggest that consideration should be given to bringing together the different groups of specialist nurses, particularly to provide cover across sickness, holidays and vacancies.

6.2 *Respiratory failure*

The non-invasive ventilation (NIV) service needs for South East Wales have been costed, and support will be instigated in conjunction with discussions around on a specialised non-invasive ventilation unit based in the respiratory medicine department at UHW.

6.3 *Cardiac failure*

Members of the Palliative Care Clinical Implementation Group in conjunction with the South East Wales Cardiac Network produced consensus guidelines on the management of end-stage cardiac failure.

Action:

The clinical guidelines were endorsed by the Palliative Care Clinical Implementation Group meeting in April 2010 and are currently being disseminated.

6.4 *Renal failure and transplants*

There have been various initiatives to improve donor rates across Wales. Following discussion between the implementation board and the transplant lead for Wales, a pilot project is being explored. This would bring the transplant coordinator into early discussions on care planning in the ICU and allow early contact with the patient's family, whilst maintaining the distinction between the transplant team and the treating team.

Action:

The All Wales Palliative Medicine Group has developed guidance on end of life care in renal failure.

The end of life care pathway now includes a prompt to the clinical team to consider whether the patient would want to be considered as a potential organ donor.

7 Children and transitional issues

7.1 Paediatric service provision

The specialty of paediatric palliative medicine is now recognised by the Royal College of Paediatrics and Child Health. The Cardiff University diploma/MSc course learning outcomes map across to the clinical competencies required of those wishing to specialise in paediatric palliative care.

Across Wales a network of paediatricians has been identified so that a minimum of one session per week in each health board will be devoted to paediatric palliative care by a local paediatrician who will have undertaken education to diploma/MSc level. This clinician links to the paediatric clinical nurse specialist, creating a network across Wales.

In addition, a lead for West Wales is now funded to provide protected time for the consultant specialist to lead on paediatric palliative care in Hywel Dda, ABMU and Ystradgynlais area of South Powys.

Action:

Education of those paediatricians and nurses who wish to undertake the training to Diploma/MSc level was funded from 2009-10.

7.2 Transitional care lead for Wales

A Transitional care lead for Wales has been appointed. It is clear that the links between paediatric and adult services have often been too abrupt for parents of severely ill young adults as these patients often have multiple complex needs.

Action:

The post is employed through Velindre NHS Trust but based in UHW to be close to the paediatric and relevant adult services, linking with those working on all aspects of transitional care and reporting to the Implementation Board.

7.3 Children's support in bereavement

The Board received a report on Bereaved Children undertaken by Jane Fitz is available on the Implementation Board website on <http://www.wales.nhs.uk/sites3/page.cfm?orgid=831&pid=36256> (a summary is in appendix 1). The report found that 22,000 children in Wales have experienced the loss of a parent or sibling, while almost 40,000 have been bereaved of a friend. A disparity of provision throughout Wales was identified and has highlighted the need for further joint working between health and education to improve access to care and support for these children, in particular for those experiencing sudden loss.

Action:

Joint working between Health and Education is planned in the coming year with an additional investigation into the needs of looked-after and refugee children, many of whom have experienced multiple bereavement and losses.

There is a need to raise awareness of children's needs when facing loss and experiencing grief. The large numbers of bereaved children suggests that normalisation of grief needs to be recognized openly in our children's services. Discussion will be undertaken with the Children's Commissioner for Wales over how best to action this in the current financial climate. The view of the Board is that this

should fall under 'Education and schools' as a responsibility because school is a fixed point in the lives of all children nationally.

7.3 Muscular dystrophy

The muscular dystrophy services development is being co-ordinated in Cardiff and Vale Health Board, in conjunction with the transitional care lead. An All Wales physiotherapy lead is due to be appointed through the team based in Rookwood hospital.

Action:

This is part of the work of the transitional care lead.

7.4 Access to clinical psychology

Progress so far

There is a serious shortfall in clinical psychology services in Wales in the cancer services. This is particularly important for teenagers and young adults with sudden onset malignancy.

The provision of clinical psychology is a core NICE standard for services.

In the current financial climate alternatives, such as training the CNSs in fundamental aspects of cognitive behavioural therapy, are being explored actively. A programme has been developed in Newcastle and it may prove cost-effective to replicate this in Wales.

Achieving Access to Excellence

During 2009, the need to strengthen our communication process to understand the barriers and levers to good care was identified as key. As the Board matures and regular visits have been carried out to providers, a body of evidence is being amassed regarding best practice and how best to deliver services across Wales. The Board has worked with third sector hospices to develop a greater understanding of the challenges facing all providers. The board has also stressed the importance of care provision that respects patients' wishes about the place of their choice for care, including dying, in all areas of Wales, both rural and urban. The Board are also better informed regarding the innovative and responsive approach teams display in achieving the best outcomes for their patients. During 2009/10 Consultant posts and increased CNS posts in all Health Board areas were set up in response to the identified need. As we enter the third and final year of incremental funding, the financial climate is changing. However, the needs of primary care teams delivering end of life care, access to generic Hospice at Homes services and those who end their lives in District General and Community Hospitals will be focused on to improve services for patient's being cared for in these environments.

It is an enormous privilege to undertake this work and to see the services in Wales improving, coming together and working to ensure that patients' care is of the highest standard whichever bed the patient is in, be it home, nursing home, hospice or hospital. Praise must be given to all who contribute in enabling the palliative care patient to experience 'a life worth living' right until the end.

The Board is most grateful to the Minister for Health and Social Services, Edwina Hart, for her close interest in the work and her constant support for this work to improve patient care at the end of life.

Appendix 1

Research into the Child Bereavement Services in Wales

Jane Fitz, February 2010

Executive summary

The need

The most recent study from child bereavement network into the backgrounds and life experiences of more than 7500 children aged 5-16 years old revealed that 1 in 29 currently of school age have experienced the death of a parent, brother or sister, and 1 in 16 have been bereaved of a friend. It would appear that;

- The number of young people and children of school age in Wales who may have experienced the death of a parent, brother or sister is 21,950 *and
- 39,800* may have been bereaved of a friend.
- Many more will have been affected by the death of someone else close.

And

- In March 2009, nearly 5000 children were in care and research has shown that bereavement may have particularly harmful implications for those who are already vulnerable, living in disadvantaged circumstances or who have experienced multiple problems.
- Those children who have been excluded from school at some point are around 60% more likely to have experienced the death of a parent, sibling or friend.*

Services available

- There is a disparity in the provision and relatively little financial support from Local Authorities or NHS Trusts. The services available are generally staffed by volunteers.
- Cruse Bereavement Care, Cymru is the only organisation offering support in every local authority in Wales, but only in Gwent is it funded for its management costs by the 5 former Local Health Boards.
- Other support is only available in 8 local authority areas.
- Evidence so far suggests there is very little support for children with special needs, those in care and their carers and all other children who are considered vulnerable.
- Those bereaved through a death from cancer have access to more support.

Role of the Assembly Government

Recent initiatives will all contribute to an enhanced awareness and access to more resources, particularly in schools.

- The School Counselling Strategy
- The guidelines in *Thinking Positively*
- The funding of a Children's Officer for Cruse

Recommendations

- The Lead Director in Children's Services in each Local Authority should establish clear lines of communication and appropriate processes within and between all the agencies, statutory and voluntary, which work with children and young adults, in order to support all bereaved children.

- Additional funding, which is cost effective and sustainable is needed from all the new Health Boards and the Local Authorities to support bereavement services by subscribing to the Child Bereavement Network, training adults working with bereaved children in the voluntary and statutory sectors and supporting the management costs for Cruse in all areas.
- Schools should provide and signpost a range of services for their pupils to access and include loss and bereavement in the PSE programmes from aged 5 to 18 so that the pupils can learn about death and bereavement as part of life. Schools should also have clear processes to identify those who are bereaved and appropriately trained adults to help assess their needs
- All schools should consider introducing the Seasons for Growth Programme.

Further Research will focus on the children with special needs who are not in mainstream education and the vulnerable and disadvantaged children in Wales who are more likely to have suffered bereavement and therefore need more support

Appendix 2

Summary of the report by Chris Lloyd Richards into CNS 7 day working

March 2010, Implementation Board

Background

This review into seven day working by Clinical Nurse Specialists in Wales was commissioned by the Wales Palliative Care Implementation Board In January 2010. The purpose of the review is to:

- Inform the Board of the current practice of Seven Day Working across Wales
- Evaluate progress towards this change of service
- Identify obstacles that are impeding the transition
- Identify pertinent issues that may affect the sustainability of seven day working in Wales.

The reviewer, Chris Lloyd Richards, was commissioned to undertake the report. She is an expert in specialist palliative care with over twenty years in palliative care management in a variety of settings. The review process undertook to:

- Establish the current delivery of 7/7 working,
- Identify areas where this is going well and where there are problems,
- Observe the service delivery at weekends,
- Produce a progress report.

Progress Report

The report maps the current working practice of seven day working across Wales, the operational delivery and where service is yet to be developed. The report details the reality of developing a seven day working specialist palliative care service, the issues of change management in large statutory organisations, areas of good practice and areas of concern. As yet it is difficult to quantify the benefit of the availability of weekend services, but qualitative data has already emerged. The report provides anecdotal evidence of the strengths and weaknesses that seven day working presents.

Strengths

- Pressures at the end of the week and the consequent higher demands of Monday morning – “Frantic Fridays and mad Mondays” – have been reduced.
- Continuity of support for patients, carers and professionals has improved
- There is a genuine desire by professionals to see this important objective implemented, and there is evidence of good will in facilitating the change.
- An improvement in patient satisfaction with the enhanced service availability.

Weaknesses

- Capacity to deliver in the long term if financial constraints decrease staff numbers
- Implementing organisational change in large statutory organisations has been slow; some managers had been reluctant to tackle resistance to change amongst staff.
- Caseload management over seven days suggests a need to review patients who are actively being seen and those who are discharged/temporally discharged (“parked”) from the service
- Difficulties accessing drugs out of hours has been highlighted. While Hospital based teams generally had no major issues, in the community accessing out of hours drugs varied widely in different areas.

- Difficulties accessing equipment emerged. Both the community and hospital teams reported significant difficulties in accessing equipment at weekends to facilitate a rapid discharge. The ease of access to equipment varies considerably across Wales.
- Access to CANISC is patchy. There are ongoing concerns in differences in how the system is used across Wales. Many teams feel that restricted access is unsatisfactory particularly at weekends. The Canisc programme manager has been made aware of these concerns.

Opportunities for sharing good practice / innovation

As a consequence of this seven day working review, opportunities for change in existing practices that can improve service delivery have been highlighted:

- Medical Admissions Unit [MAU]: There was very little presence of the SPCT in most acute Medical Assessment Units. Raising the awareness of the weekend service in MAU can avoid inappropriate admissions to acute hospital wards. Teams should be encouraged to provide a service in this area. Raising the awareness of the weekend service in MAU can avoid inappropriate admissions to acute hospital wards. Issues such as symptom control can be addressed without waiting until Monday. The knock on effect is that it is often possible to facilitate an early discharge back home, to the care of district nurses and community palliative care teams.
- Access to District Nurses/Rapid Response/Marie Curie Nurses: There were a variety of services available in the community such as District Nursing, Marie Curie, Red Cross, Rapid response. However services were not seamless or equitable. Examples of good practice focused on keeping a patient at home, e.g. Marie Curie is commissioned to provide an out of hours' rapid response palliative care service in some areas of North Wales. There was a consensus opinion that better home care support would contribute to easier discharges of patients and would also help avoid some inappropriate [re]admissions to hospital. Many patients discharged require the sort of care that could be provided by a health care support worker, but currently they are not available in most areas. This needs immediate consideration.

Conclusion

This report is the first stage in a review of how teams across Wales have approached implementing seven day working; the plan is to repeat the review in a years time or overall, clinical nurse specialist showed commitment and innovative approaches to the way that they are working. In the community, the team's base varied, depending on local resources, for example the ability to be based with out of hours services.

It is too early to provide robust evaluation of this change in working practice, although those working at the weekend had reported the appropriateness of referrals that they had seen and there were several individual patients where the intervention of the CNS had been critical; the outcome in some difficult clinical crises would have been adverse if the CNS had been unavailable.

There is a genuine desire to see this important change succeed, and there is evidence of good will. Close monitoring, collection of quantitative data of weekend activity and outcomes is important to provide evidence to inform service planning.

The Implementation Board strongly recommends repeating this review at the end of this year.

Appendix 3

Funding for 2010-11

Voluntary sector direct Hospice Funding 2010 -11

Area Hospice	2010-11 Recommended Spend £000	Funding Objectives Include
<i>Betsi Cadwaladr</i>		
St David's Hospice, Llandudno	222,480	Develop integrated service and support working by CNS with Llandudno hospital; develop nursing workforce; maintain 10 palliative care beds with OoH emergency admission; provide clerical support to clinical team; maintain enhanced AHP provision; pilot one respite care bed; moving consultant to be fully NHS funded
St Kentigern's	100,000	Review service provision; provide 8 spec palliative beds with OoH emergency admission; provide clerical support to clinical team
Nightingale House	86,500	To lead on NIV and cardiorespiratory expertise in nursing and AHP across Wales; commission work on CaNISC roll out; clerical support to clinical team; medical support costs.
Gwynedd Hospice at home	90,000	Maintain hospice at home services across NW Wales; support medical training and 24/7 on-call; develop clinical team across NW Wales with St David's hospice; all Wales audit and support end of life pathway
Ty Gobaith	175,000	Provide educational lead for paediatric palliative care nursing, working with Ty Hafan.
<i>Powys</i>		
Severn Hospice	18,500	Support the multi-professional team in North Powys
Usk House	5,000	Maintain non-cancer patient support in South Powys
<i>Hywel Dda</i>		
Beacon of Hope	67,000	Develop multiprofessional service in Ceredigion linking with Gwynedd and Severn hospice; outreach CNS into Machylleth; health care assistant to specialist team – community
Shalom House Hospice	95,000	To develop multi-professional service in West Hywel Dda
Paul Sartori Foundation	100,000	To develop hospice at home and specialist nursing to support patients at home as part of managed clinical network
Ty Bryngwyn	50,000	To explore opening, currently closed beds to increase cost efficiency of the unit; provide coordination of medical and nursing leadership across Hywel Dda
<i>ABM</i>		
Ty Olwen	65,000	Develop an integrated service across Neath/Port Talbot; establish training days for health care support workers; ensure roll out

		of integrated care pathways across ABM
Cardiff and Vale		
Holme Tower	166,000	Maintain 7 day CNS working with GTHC; increase service access for non-cancer patients; Liaise regarding guidelines for NIV with Nightingale House continue development of End of Life Care specialist services
George Thomas Hospice Care	55,000	Establish 7 day CNS working; increase service access for non-cancer patients; support development of training posts in palliative nursing; consultant cover; ensure linked nurse to each nursing, EMI and residential home.
Ty Hafan	110,000	Increase integration with paediatric services with consultant lead; wider respite availability; wider range of on-site treatments.
Aneurin Bevan		
Hospice of the Valleys	50,000	Transition to full 7 day working
St David's Foundation	280,000	7 day service in South Powys; devel integrated service with heart failure, neurological disease and Marie Curie; increase palliative care training for CNS staff over the next 3 years; develop AHP service in community
St Anne's Hospice	286,000	3 respite beds; develop relationships with Cardiac and renal failure teams; development of service esp neurological care; rotation of band 6 nursing staff with Royal Gwent
TOTAL	2,021,480	

In addition, consultant posts previously funded by the voluntary sector will be directly funded by the NHS.

This provides an additional benefit to the hospices of £480,080.

This had previously been an expense borne by the independent hospices.

Thus the total financial support to the voluntary sector is £2,501,560, in addition to the Health Board funding agreements that are in place.

Appendix 4

One Wales funding to Health Boards

Allocation of One Wales funding 2010/11

2010/11 recurrent funding (full year costs)		Funding objectives
<i>Capital</i>	<i>Revenue</i>	
BCU		
	£40,000	Funding for previously vulnerable post of CNS
	£27,500	Costs for 7 day working across North Wales (10k/sector/yr) due April, May & June 2010
	£80,000	SpR post in North Wales
	£10,000	Paediatrician palliative care medicine session
	£20,000	CALL 24-hour All Wales helpline for patients and carers
	£27,000	AHP sessions for Conwy, Denbigh
	£20,000	Data entry clerk in Glan Clwyd
	£100,000	Consultant post in NW Wales/Llandudno
	£10,000	Additional clinical session Mid BCU
	£17,520	Consultant recharge to Cardiff University
	£34,000	NHS funding consultant with additional session
Powys		
	£8,000	Paediatric specialist palliative care nursing training x 2
	£4,000	Paediatrician palliative medicine education
	£65,000	All Wales service development and clinical support
	£20,000	Data entry clerks/medical secretaries
	£28,000	0.6 CNS in Knighton area
	£10,000	Support for 7 day working
	£6,000	Weekly consultant in S Powys from Hereford NHS Trust
Hywel Dda		
	£100,000	Consultant post in Bronglais –in-reach to S. Gwynedd
	£9,000	Costs for 7 day working
	£56,000	Shalom medical cover to Pembroke palliative care services
	£20,000	Data entry clerk
	£38,000	Lead paediatric specialist palliative care nurse
	£15,000	Paediatrician palliative medicine sessions
ABMU		
	£38,000	Lead paediatric specialist palliative care nurse & education
	£30,000	Paediatrician palliative medicine session &

		South Wales regional lead
	£100,000	Consultant post for Neath Hospital/community
	£30,000	7 day working in each of 3 areas (Swansea/NPT/Bridgend)
ABMU / Informing Healthcare		
	£248,000	CaNISC development of module
£68,000		CaNISC Capital
	£48,000	CaNISC staff training costs
	£45,000	CaNISC core service charge
	£7,000	CaNISC software
Cardiff and Vale		
	£10,000	Support for 7 day working
	£37,000	OT in team
	£47,000	1 additional CNS to meet bed number workload
	£35,000	Secretarial/data entry CaNISC coordinator UHW & Llandough
	£38,000	Physio for muscular dystrophy
	£14,000	Paediatrician muscular dystrophy session & education
AB (Gwent)		
	£10,000	Support 7 day working Gwent Hospitals
	£10,000	Paediatrician palliative medicine session
Velindre NHS trust		
	£43,000	CNS training post & 7 day agenda for change costs
	£18,700	iWantGreatCare evaluation of services
	£3,000	Dying Well Matters
	£11,000	Child bereavement service rollout
	£1,000	Patient held card
	£32,000	Implementation Board administration and costs
	£2,320	Link for E-learning for Health website
	£40,000	HCA x 2 for discharge
	£130,000	Consultant post to Llandough Hospital, Holme Tower and neurology services
	£43,000	Consultant in South Powys
	£60,000	Powys consultant based at Severn Hospice
	£288,560	Consultants previously funded by Marie Curie
	£460,000	Consultant posts in Aneurin Bevan
	£80,000	SpR in community transferred from GTHC
	£56,000	Additional medical support to secondment of Prof Finlay
	£72,000	Transitional care lead
	£92,164	Neurological disease network initiative including NIV development and O.T. coordination
	£20,000	Data entry clerk for CaNISC
	£20,000	Consultant clinical sessions for CaNISC
	£40,000	Education for primary care staff inc. nursing homes.

Cwm Taf		
	£56,000	Increase consultant input to Royal Glam Hospital
	£32,000	Increase medical cover in Merthyr
	£20,000	Data entry clerk
	£34,000	Increase medical support to consultants
	£78,000	Care assistants x3
	£41,000	Clinical Nurse specialist band 6 – Merthyr
	£2,000	Website support
	£54,000	1WTE physiotherapy
	£53,000	O.T. 1WTE in S Cwm Taf
	£38,000	Lead paediatric/transitional specialist palliative care nurse
	£10,000	Paediatrician palliative medicine session & education
Other pan-Wales developments		
	£1,122,000	Healthcare Assistants for DGH palliative care teams
	£301,756	LHB to fund professional gaps for non-cancer and out of hours pharmacy.
Totals		
£68,000 capital	£4,866,520	