Dying Well Matters

One Wales: 3 years on

(2008 – 2011)

“How people die remains in the memory of those who live on.” Cicely Saunders 1918-2005
Introduction

The Wales Palliative Care Implementation Board was established in July 2008 by the Minister for Health and Social Services, Edwina Hart. The prime focus of the Implementation Board is to achieve the recommendations of the Report of the Palliative Care Planning Group chaired by Viv Sugar (2008). Every aspect of the work of the Implementation Board is underpinned by an assumption that good quality end of life and palliative care should be readily available, universally across Wales. This report details the work undertaken through the Palliative Care Implementation Board to achieve the recommendations of the Sugar Report over the period 2008-2011. The report identifies the need to build teams and services robust enough to take on the challenges of improving end of life care for all in Wales into 2020.

It has been an enormous privilege to work with the Implementation Board and lead this work, and to see the services in Wales improving, coming together and working to ensure that patient care is of the highest standard, which ever bed the patient is in, be it home, nursing home, hospice or hospital. The Board members, Independent Hospices Cymru and the Palliative Care Implementation Group of Health Board leads (PCIG) have shown dedication, hard work and true partnership in making this work succeed. Praise must be given to all who contribute in enabling the palliative care patient to experience ‘a life worth living’ right until the end.

None of this would have happened without the Minister’s unfailing support of the work of the Board and her deep commitment to improve end of life care across Wales for patients and their families.

Professor the Baroness Finlay of Llandaff
Board Members
Marion Andrews-Evans (Senior Nurse, Welsh Assembly Government)
Viv Cooper (Lead Nurse, Velindre Hospital)
Alun Davies (Chief Executive, St David’s Hospice, Llandudno, a voluntary sector hospice) from 2009
Gillian Evans (Chair, North Wales Patient Forum) from 2009
Baroness Finlay of Llandaff (Professor of Palliative Medicine, Cardiff University and Velindre NHS Trust) – Chairman
Dr Andrew Fowell (Consultant in Palliative Medicine, Betsi Cadwaldr Health Board) – Vice Chairman
Dr Helen Herbert (GP Aberaeron, immediate past-Chair of RCGP Wales)
Bernadine Rees (Director of Primary Care, Community & Mental Health Services, Hywel Dda Health Board) from 2009

Secondees to support the work of the Board:
Veronica Snow (Lead Nurse Specialist Palliative Care, Powys Health Board and SW Wales Cancer Network)
Lisa Miller (Manager, Velindre Hospital)

Past Board Members:
Dafydd, Lord Wigley, Lay member, 2008-2008
Paul Williams, Chief Executive NHS Wales, 2008-2009

The Voluntary Hospice Movement
The contribution of voluntary sector organisations to palliative care in Wales cannot be overstated. Hospices have a long tradition of placing the needs of patients and carers first, securing funding streams later. They have relied greatly on the generosity of the Welsh public to maintain these services. Partnership working with individual hospices and through the Welsh hospices umbrella group Independent Hospices Cymru has resulted in progress towards ensuring the recommendations of the Sugar report are achieved in full and has been underpinned by agreement of a funding formula that compensates hospices for core service provision in a way significantly fairer than any previous arrangement.

"Independent Hospices Cymru welcomes the work of the Implementation Board, in particular, focusing on delivering equitable services throughout Wales. We are grateful that there has been recognition of the unique and valuable contribution of voluntary Hospices in Wales and welcome the opportunity to continue to play a significant role in service planning and delivery in the future"

Emma Saysell
Chair Independent Hospices Cymru
Chief Executive St David’s Foundation Gwent
**Background**

**Setting the strategy**

In its publication ‘One Wales – A Progressive Agenda for The Government of Wales’ (2007) The Welsh Assembly Government endorsed the principle that, in building a world-class health service, care should be available to everyone, irrespective of who they are or where they live in Wales, at the time of need (One Wales 2007).

There was already substantial evidence to suggest that in palliative care, this was not the case. Inequalities in provision of palliative care had been identified earlier (Tebbit 2005); the ‘One Wales’ programme provided dedicated palliative care funding to address these inequalities. This was an important step towards ensuring that good end of life and palliative care could be available, universally across Wales, to patients of all ages.

The Minister for Health and Social Services, Edwina Hart, quickly established a palliative care review group, chaired by Viv Sugar, CEO of the Welsh Consumer Council. Recommendations from the review were published in July 2008. The Minister accepted the recommendations and appointed Professor Ilora Finlay to establish the Wales Palliative Care Implementation Board to implement the recommendations on behalf of the Welsh Assembly Government.

<table>
<thead>
<tr>
<th>Viv Sugar</th>
<th>Ilora Finlay</th>
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<td>Chair of the Palliative Care Planning Group 2008</td>
<td>Chair of the Palliative Care Implementation Board 2008</td>
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Wales Palliative Care Implementation Board

The prime focus of the Implementation Board is to achieve the recommendations outlined within the Palliative Care Planning Group Report (2008) chaired by Viv Sugar. The work of the Implementation Board is underpinned by the following core principles agreed by the Board and Palliative Care providers across all sectors:

- Good end of life and palliative care should be available, universally across Wales.
- 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 provided by the NHS or by voluntary sector providers, is essential for high standards in care.

The Board meets on a quarterly basis and has held meetings in South East, South West and North Wales, with public meetings in Wrexham and Llanelli. Members of the Board have conducted visits annually to all services in Wales. A conference to share the work of the board and listen to stakeholder views on palliative care was held in June 2010. To ensure cost effectiveness, meetings have been held at NHS and Hospice locations throughout Wales.

Baseline of services in 2008

It was obvious from the outset of the Palliative Care Implementation Board that there were some excellent established services, while in other areas there had been little investment in palliative care. The Palliative Care Implementation Board resolved that, while fairness of service provision was a core principle, this needed to be achieved without restricting the leading specialist palliative care service providers in Wales, who had already developed and established evidence-based services.

Voluntary sector organisations, historically the vanguard of the hospice movement, had developed services in parts of Wales that were locally supported and comprehensive. The funding received from Health Boards in Wales to support these services was inconsistent and sometimes inadequate to meet the cost of delivering the service, although this was not the case in all areas. Even where funding was more substantial, there was no effective performance monitoring in place to ensure cost effectiveness of services, and governance structures varied.

Since 2004, £2million ring fenced funding had been provided annually from the Welsh Assembly Government to Voluntary Sector hospices in Wales through a bidding process. The Welsh umbrella hospice organisation Independent Hospices Cymru and the Palliative Care Implementation Board agreed that while the additional funding had been welcome, this process did not provide stability for hospices and was not being best utilised to invest in much needed evidence-based core services.

Fairness also required establishing services in areas where an absence of voluntary sector hospice presence had resulted in chronic under investment in core services and in some services falling short of an accepted standard. Services in these areas had not received investment to keep pace with the growing need of an increasingly ageing population and those whose treatment helped them live longer, but with ever more complex palliative needs. Nor had the palliative needs of the non cancer
Dying Well Matters in Wales – 3 years on

disease population been taken into account. Services to children, adolescents and young adults had not been considered as an integral part of the spectrum.

**Objectives**

Fairness of provision, as a principle, was a key marker by which the Palliative Care Implementation Board decided to evaluate their decision-making. To establish a network of palliative care service across Wales that is fair, universal and fit for the future, the Palliative Care Implementation Board began work on key objectives:

1. Access for patients with complex needs to specialist palliative care on a 7-day a week basis, with advice available to all clinical teams in Wales on a 24/7 basis.

2. A funding formula that would determine how to fully fund core, evidence based services, delivered by both statutory and voluntary sector organisations that was fair and equitable, while taking into account variables such as access to specialist care in rural areas and the demand on services in areas of urban deprivation and social isolation. The funding formula would endeavour to ensure a minimum level of specialist service across Wales. The formula was welcomed by voluntary sector hospice organisations as it provided a level of financial stability.

3. Development of CaNISC as an electronic patient information system that would improve care through access to patient information.

4. Standards that would determine a set of Quality Outcome Measures to ensure the services delivered were fit for purpose and appropriate to the needs of the population. The standards should be applied universally to monitor the quality of care in all settings.

5. Service Specification to clarify the expectations on those delivering the services and act as a method of performance management, ensuring service delivery meets expectation and the services meet the requirements of the agreed standards.

6. Public engagement, using patient/ carer and public feedback to monitor that services continue to meet the needs of patients, using this information to modify or change services as necessary.

7. Establish a Palliative Care Research Network. Driving up standards of care through evidence, and to provide a focus of enquiry, providing solutions to problems encountered by patients with advanced disease.

The initial remit of the Palliative Care Implementation Board was to implement the Sugar Report’s recommendations, which had set out priorities as short, medium and long term goals. By 2009, the medium and short term objectives had been achieved, allowing the Board to focus on the future direction of end of life care.

In addition, as work continued, it became apparent that good quality end of life care for all, required changes in areas not addressed by the Sugar Report, e.g. the needs of bereaved children, wheelchair
services for palliative care patients and the role of Day Care in end of life care. Work in these areas was incorporated into the work of the Palliative Care Implementation Board.

The Sugar Report highlighted an area of evident need that required a specific focus on non-malignant disease. Historically cross referral rates to palliative care had been low, despite an increasing numbers of patients with life-limiting non-malignant disease, including those with dementia, evidently requiring better end of life care.

Creating meaningful change in the way we care for those with palliative care needs through the implementation of the recommendations of the Sugar Report (2008) was only the first stage. Sustaining good services and modifying change to ensure services are fit for purpose will require ongoing assessment and evaluation.

User evaluation through iWantGreatCare (iWGC) and Dying Well Matters (DWM) was set in place to ensure services are receptive to patient need in the long term. In the future this will be combined with standards monitoring through a peer review quality assurance process in which all services will require accreditation from Health Inspectorate Wales. These strong foundations will underpin access to end of life care, fit for the future for all, wherever they may reside in Wales.
Leading as a Nation
As the work of the Board progressed, Wales was evolving solutions to problems that also concern our neighbour nations in other parts of the United Kingdom and wider.

End of Life Care Boards also exist in England, Scotland and Northern Ireland, so a Four Nations group was established to share information and ideas to improve palliative and end of life care. Wales has shared its achievements and offered national colleagues potential solutions to various aspects of service change.

There has been much interest in the Welsh Funding Formula, in the baseline of the service that should be available for a given population, and in how the Board has achieved implementation of change at a rapid pace. Particular interest has focused on 7-day working by clinical nurse specialists, Wales being the only nation to have implemented this comprehensively.

Evidence has been provided to the English Palliative Care Funding Review group regarding the details of developing and managing a valid funding formula. The Department of Health commissioned a Palliative Care Funding review group in 2010 to which Baroness Finlay, on behalf of the Palliative Care Implementation Board, was able to provide substantial evidence.

The Welsh Integrated Care Pathway for the last days of life document has been revised and improved. There have been requests to share this work both nationally and internationally.

The iWantGreatCare programme is the first national agreed service evaluation implemented by all specialist palliative services. Colleagues in other nations and in different disciplines are particularly interested in this area of evaluation.

A Palliative care section has been developed for the computerised clinical database, CaNISC. This is now used by all specialist palliative care providers to register patient contacts, allowing round the clock access to clinical records and ensuring data is collected in a standard format, which will allow meaningful benchmarking of services.
Establishing Clinical Networks

Robust evidence based clinical services require strong clinical leadership, to ensure standards are maintained, to be innovative and to introduce change as required to meet service need.

A direct link between the Palliative Care Implementation Board and each Health Board’s palliative care clinical leads (medical, nursing and managerial) was established in October 2008 through the Palliative Care Clinical Implementation Group (PCIG). The PCIG’s role is to carry forward the work of the Implementation Board locally at Health Board level. The Health Board clinical leads have a clear remit to improve palliative and end of life care, working with all providers, through a series of task and finish projects.

Paediatric and transitional care of children and young people with life limiting conditions have been a focus of service development, with each Health Board having one or more named paediatricians and paediatric specialist nurses with sessional commitment to end of life care. These paediatricians and specialist nurses have all started training on the Cardiff University MSc in Palliative Care (paediatric modules). A Paediatric PCIG has also been established to ensure cohesive developments, including cross cover arrangements, across Wales.

The purpose of the Clinical groups is to:

- Integrate local services
- Establish commonality of working practices across Wales
- Pool rotas of clinical staff and establish staff rotation
- Undertake Health Board wide audits and quality control
- Contribute to national work programmes
- Financial monitoring, particularly of services with multiple funding streams, ensuring value for money
- Work in partnership, both locally and nationally, with all providers both statutory and voluntary sector

The PCIG has streamlined reporting and replaced the three regional cancer network palliative care groups, cancer services coordinating group, palliative care advisory group and the regional planning forum.
Building Teams fit for the future

The impact of specialist palliative care multidisciplinary teams on improving outcomes for patients is well documented (NICE 2003). The challenges facing palliative care services as we move into the next decade will be how to maximise and maintain the increasingly varied range of skills and expertise required within multidisciplinary teams to improve end of life care for all, in particular:

- Reaching the non cancer palliative care population
- Supporting an increasingly ageing population, living longer with co morbidities
- Improving the quality of life for younger patients living longer requiring complex management

An increased demand for direct patient care will be matched by the requirement to support and advise other professional teams caring for patients with complex end of life care needs, e.g. renal, cardiac and critical care teams. To meet these challenges, the specialist palliative care multidisciplinary team need a full range of professional expertise, delivered within a good governance framework, supported by strong clinical leadership.

Investment in full specialist multidisciplinary teams was required. A priority for the Palliative Care Implementation Board was to establish multidisciplinary teams as a priority throughout Wales.

Investment to build effective teams required the appointment of:

- Consultants in palliative medicine – 17.8 wte of which 11.8 wte required new funding
  - This includes: Consultant lead for transitional care for teenagers
  - Paediatric leads for each of the Health Boards
  - Specialist training post for one year in West Wales
  - Moving all consultants onto NHS contracts
- CNS posts – 13 full time equivalents
  - This includes: 4 paediatric posts
  - Plus additional funding to each adult CNS team to provide 7-day working
- Allied Health Care professional posts – 8.04 whole time equivalents have been funded to ensure that specialist services are able to access input from physiotherapy and occupational therapy
- Investment in Data Clerks - a total of 15 data clerks posts have been funded to ensure CaNISC entry is accurately entered.
- Health Care support workers – a total of 17 whole time posts have been funded for health care support workers, the majority will work primarily with specialist teams in hospital inpatient settings

Voluntary sector hospices received additional investment to increase their CNS establishment, support their contribution to 7-day working and improve access to Allied Health Professionals.
### Posts (NHS and Voluntary sectors)

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<tr>
<td>Consultants</td>
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<tr>
<td>CNS</td>
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<tr>
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<td>7/7support</td>
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#### Plus:

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<th>Aim of funding</th>
<th>Total funding</th>
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<td>Paul Sartori Foundation</td>
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<td>Holme Tower Hospice</td>
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<td>Hospice of the Valleys</td>
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<tr>
<td>St David’s Foundation</td>
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The right place at the right time

Inpatient services

Most patients express a preference to be cared for in their own home. In reality, this is not always the most suitable place of care for all patients all the time. Complex symptom management can often be more easily achieved within a hospice setting. Sometimes care at home can break down for several reasons and the opportunity for specialist respite at this time can mean the difference in getting the family back on track and complete care breakdown.

While the number of inpatient beds across Wales appeared to meet the current need, funding for these beds was inadequate.

In time, the requirement to deliver palliative care for all, regardless of disease will increase the demand on beds, particularly respite beds for non cancer patients. Funding has now increased the bed allocation allowance for each Hospice; those with the capacity to increase beds to support planned respite for non cancer palliative patients have had their bed allocation increased pro rata. A bed allocation allowance is also ascribed to ‘notional’ beds for teams delivering Hospice at Home services instead of actual in-patient hospice beds.
**Home Care**

Most patients express a wish to be in their own homes as much as possible, but they and their families are often fearful of the unknown and worry about what may happen if the condition suddenly worsens.

The Board has worked with community teams to help them establish joint working across 7-days, ensure all specialist nurses have the necessary skills and competencies required to practice at specialist/advanced level and are educated to the standards defined in The Career Framework for Nurses in Wales (WAG 2009).

Each community CNS is linked to one or more local nursing homes, with the remit to take forward improvements in nursing homes in end of life care and to empower staff to care for dying patients, using the Welsh Care Pathway, rather than feel they have to send residents into hospital even when the death is clearly expected.
Hospice at Home

Hospice at Home services run in several parts of Wales, providing expert care to patients in their own homes instead of in a hospice ward. This enables many patients to return home from hospital or to remain at home who otherwise would require in-patient care. These services are particularly supportive in rural areas, so the Board is working with stakeholders in Powys to create a hospice at home service. Hospice at home services are established in Pembrokeshire, Ceredigion, Gwent, Gwynedd, and Flintshire.

Marie Curie Nursing Service

Home care in all parts of Wales is supported by the Marie Curie Nursing Service, working in conjunction with other voluntary sector and NHS services. Over the last three years Marie Curie nursing has extended support to patients with non cancer palliative care needs. This increase in activity has required One Wales funding, through the Board, annually to supplement the existing agreements between the Health Boards and the Marie Curie Nursing Service across Wales.

Numbers of patients who received Marie Curie nursing at home
Hospital Support Teams

Support teams have had their staffing levels increased to support 7-day working; they are now piloting the inclusion of health care assistants to supplement care for those with very complex problems on hospital wards.

"I have not come across any patients with exclusive palliative care needs over the holidays. Fantastic service for the patients and their family, on what will often be their last Christmas together".

Duty general medical consultant at Ysbyty Wrecsam Maelor, commenting on the difference at Christmas 2010, compared to previous years

The introduction of 7-day working has been shown to have a major impact on supporting those with complex needs, in avoiding hospital admission of patients through accident and emergency departments who want to be supported at home. Other notable improvements have been in detecting treatable conditions early, thereby avoiding major crises such as paraplegia from spinal cord compression.

Day Hospice Services

Hospices offer a variety of services that improve the quality of life for palliative patients outside the main inpatient units, often in a day care setting. It is recognised many of these treatments and therapies contribute to patient well being and satisfaction. Without any clinical evidence base, these valuable services rely heavily on the generosity of the public.
Achieving Access to Excellence

A ‘Palliative Care for all’ approach must consider how access to specialist palliative care services is offered to best support those with a non cancer diagnosis. The needs of this patient population will differ widely, both in terms of length of input due to disease trajectory and intensity of support for a potentially wide range of symptoms. A priority of the Palliative Care Implementation Board was to strengthen specialist palliative care teams to meet this challenge. This was done with direct investment in teams throughout Wales. This was the first stage and further work was needed to identify how best to support these patients, both directly and more importantly indirectly through the disease specific professional teams caring for these patients with end of life care needs.

An End of Life summit was held in November 2010 to bring together the major groups representing non cancer palliative care patients. The meeting began a programme of work which will be significant in ensuring one of the most important principles that good end of life care should be accessible to all.

Achievements in this area to date include:

- Linking with clinical networks to develop common referral policies, guidelines and protocols
- Engagement with all specialist clinical teams who support patients with a potentially life limiting diagnosis
- Formally recognised links established between Clinical Nurse Specialists delivering cancer and those delivering non-cancer palliative care, which are monitored annually by the Implementation Board
- Guidelines on the management of end-stage cardiac failure agreed between the Cardiac Network and the Palliative Care Implementation Group
- Meetings with the cardiac specialist nurses and with the neurological alliance have informed closer working between the specialist nurses.

A UK think-tank on motor neurone disease (MND) in 2009 produced a charter for care of MND patients, with a version tailored to recognise the developments in Wales.

Primary Care Investment

The majority of patients who require Palliative and End of Life Care will be cared for in the community by their Primary Care Team. The Palliative Care Implementation Board recognised the need to ensure these teams of GPs, Community Nurses and Allied Professionals are supported through the increased availability of Specialist Palliative Care Teams and Hospice at Home services throughout Wales. Primary Care teams themselves also need to be equipped with the skills to care for these patients, manage their symptoms and refer on to Specialist Palliative Care as appropriate. Work was therefore undertaken with the Royal College of General Practitioners (Wales) and a group of General Practitioners with a special interest in end of life care, to consider how to address the educational needs within primary care teams.
A series of three conferences across Wales were held during 2010. These were funded by the Palliative Care Implementation Board and hosted by RCGP Wales. Over 200 delegates attended. The multi-professional audience explored end of life related topics, including:

- The Gold Standards Framework
- General Medical Council’s ‘End of Life Care Guidelines’
- Advance care planning
- Symptom control
- Audit in end of life care
- Educational/training needs in Primary Care

The Palliative Care Implementation Board provided funding through the Royal College of General Practitioners in Wales to support practices by purchasing, for every GP in Wales a copy of the ‘Adult Palliative Care Guidelines’, as agreed across the United Kingdom.

Funding was also made available to deliver The Gold Standards Framework Primary Care training module: ‘Going for Gold’. This training module has been delivered in eighteen practices across Wales by a team of GP and Nurse Facilitators, funding for these posts has also been supported by Macmillan Cancer Support. To date, sixteen practices have completed an ‘After Death Analysis’ which allows primary care teams to self assess the end of life care they provide to patients and their families. The analysis will be repeated following the completion of the training module. Forty Six training sessions have been delivered and all the eighteen practices are expected to complete the module by March 2011.

In addition, a short-course for General Practitioners in palliative care was developed by Cardiff University in conjunction with General Practitioners.

After piloting and modification, the course has run across various venues in Wales, providing 40 Masters level transferable credits to those who complete the course and the assessment. Uptake has been enthusiastic and to date over 150 GPs in Wales have enrolled on the short-course. Macmillan Cancer Support provided bursaries to enable General Practitioners to attend the course.
Negotiations have also been undertaken with the Quality Outcomes Framework (QOF) team at the Department of Health to try to increase the recognition of the role of Primary Care in End of life care as part of General Practice ‘QOF’ contract.

There are many examples of good practice in end of life care in Primary Care. Maintaining a palliative care register of palliative care patients as part of the existing ‘QOF’ contract is already in place. Regular multidisciplinary team meetings to discuss these patients are developing rapidly. The work being undertaken plans to embed the principles of planning and preparing to support patient choice in end of life care in all settings.

**Training and Education**

In addition to undergraduate education, the Board has focused on improving training of qualified staff in the core requirements in palliative care, training at higher specialist levels in nursing and medicine and improved skills in the workforce already working at specialist level.

The Masters programme in palliative care at Cardiff University has been important in this development. This course, which started in 1989, has remained well evaluated and well attended, with healthcare professionals from all over the world coming to Wales to study. Every effort has been made to ensure that healthcare professionals in Wales who wish to study on the course are able to access support in the workplace and bursary support to attend the full programme.

Other important areas of training include the Cardiff University undergraduate programme in the medical curriculum. Increasing efforts have been made to obtain palliative education sessions on undergraduate and postgraduate nursing courses.
**Accredited Services**

**Standards in palliative care**

The Palliative Care implementation Board found that the existing methods of evaluating services and monitoring of standards compliance did not fully reflect the changing nature of end of life care services. There were also gaps between those regulated by Health Inspectorate Wales and those monitored for compliance against the Welsh National Standards in Palliative Care for Cancer Services e.g. Services provided in a community day hospice setting did not require any regulation.

A workshop was held in 2009 with the relevant bodies and the standards subgroup of the Implementation Board to develop joint standards. It was agreed that core standards are required specifically for inspecting all general services in all settings, and additionally for inspecting hospices/specialist palliative care providers.

A joint working group between the Palliative Care implementation Board, Health Inspectorate Wales and the Welsh Assembly Government department ‘Standards for Health Services in Wales’, led by Dr Andrew Fowell, delivered a robust set of end of life quality markers from which to develop outcome measures to monitor standards. Following a period of consultation, this single document will form the basis of all future assessment and monitoring of services across all areas providing care for patients at the end of life. The ‘End of Life Quality Markers’ document takes account of direct user feedback of services, through the Dying Well Matters programme.

In time it is expected that the monitoring process will form a component of an All Wales Palliative Care Peer Review process for specialist services.

**Service specifications and funding agreements**

A model service specification reflecting the new standards in palliative care was developed by a subgroup of the Palliative Care implementation Board for use by Health Boards. The specification outlines what is expected of a specialist palliative care team, covering all aspects of the team including expected level of service delivery and qualifications of the professional team members.

Compliance with the service specification will be applicable to all specialist palliative care providers, both the NHS and voluntary sector. The adoption of the service specification will contribute to fairness and equity of access by creating a consistency of service provision across Wales, compatible with the standards against which services will be accredited.

**Raising standards everywhere**

The inspection process for registration of all clinical services was reviewed with Health Inspectorate Wales. New patient focused standards have been written which all patient services in Wales will be expected to meet, whether in-patient, outpatient or day treatment services, residential or nursing home care or other places of care. These have been written from the perspective of what patients should be able to expect from all NHS and non-NHS care providers in Wales in relation to end of life care needs.
Working with Technology

Clinical Information System (CaNISC)

The Sugar Report recommended that an existing information system be developed to provide access across all sectors to key clinical information and link to a single assessment process. The Implementation Board put significant funding into the development and implementation of a palliative care computer patient record as part of the clinical management system (CaNISC), suitable for use in all specialist palliative care clinical settings.

A clinical lead and a project manager were appointed along with a voluntary sector ‘champion’ to drive this important piece of work. The system ensures that relevant information on referral, treatment and investigations can be readily accessed by all specialist palliative care teams caring for the patient at any time. All such providers can now access the patient record and all palliative medicine consultants in Wales have secure laptops to access patients’ records to ensure they give relevant advice 24/7. Further investment in data entry clerks has been made to sustain this important work.

Web Advice

A dedicated website has been developed by Dr Ian Back (Clinical Lead, Cwm Taff Health Board) to provide an open access, one stop source of information about palliative care matters in Wales. It has been developed through an iterative process with the consultants in palliative medicine in Wales and is accessible for any health care professional or lay person.

The site includes on-line access to palliative care management guidelines agreed across Wales, information of syringe driver drug compatibilities, an on-line opioid dose converter to avoid drug dosage errors and links to key publications, other websites of relevance and current meetings.
Reliable Service 24/7

Making important clinical information available at all times

A dedicated palliative care module has been developed as part of the CaNISC computerised cancer patients’ clinical record system. The module is designed to hold consistent registration details for all diagnoses, not just cancer, and to also record the first clinical assessment after referral.

It is linked to voluntary and statutory sector providers to improve communication by enabling important clinical details to be available across providers. Secure computers and associated connections have been provided to all voluntary sector and NHS specialist palliative care providers, with training and support to clinicians and dedicated funding for data entry clerks.
Care Out of Hours

Clinical Nurse Specialists: 7-day working

The Welsh Cancer Palliative Care Standard and the NICE supportive and palliative care guidelines required that 7-day working be introduced by clinical nurse specialists working in palliative care by March 2009.

In September 2009 a Ministerial letter reinforced out-of-hours care as a priority across Wales, with 7-day working by all palliative care teams expected by March 2010. Some teams embraced change and novel ways of working more rapidly than others. However, by September 2010 all teams were participating in 7-day working.

The 7-day service has been independently reviewed, with an initial review of the value of 7-day working undertaken in 2009. This reported a definite improvement for patients, particularly those admitted into Accident & Emergency units and Medical Assessment Units. Closer working between the specialist palliative care teams and hospital admission units was also reported, providing opportunities for case finding and informal teaching. Teams report satisfaction in being able to oversee care for patients over weekends. This review is currently being revisited and will report early 2011.

“We should have done this long ago; we’ve got rid of frantic Fridays and mad Mondays”.

CNS from hospital support team. December 2009

The Palliative Care Implementation Board approved increased investment in clinical nurse specialists and service costs to assist in introducing this change in working practice. 7-day working is now established as a core criterion in all funding agreements for specialist palliative care services.
Consultants on call

Consultants in palliative medicine participate in on call rotas to provide advice to any health care professional at any time. These consultants have been provided with laptops and secure connection codes to allow access to clinical records if advice is sought by a health care professional.

Access to Drugs

Difficulties accessing drugs out-of-hours were highlighted by patients and specialist teams. A pharmacist who has also specialised in palliative care has undertaken a project to provide ‘Just-in-Case’ boxes across Wales. These will be standard boxes containing a core minimum of drugs that are likely to be needed in the event of a patient at home deteriorating. These drugs can be used in conjunction with the Welsh End of Life Care Pathway. These should be available and rolled out across Wales by April 2011.
Listening to patients and carers: Learning and changing through the patient experience

Two major developments were instigated to capture the patient voice.

‘iWantGreatCare’

As part of the palliative care implementation work programme, the opportunity to participate in an independent ongoing nationally benchmarked survey was welcomed. iWantGreatCare, an organisation with experience of evaluating patient feedback on clinical performance, has worked with the Implementation Board to develop a straightforward system to capture the patient’s view of the care they experienced from their local specialist palliative care teams.

The simple forms are offered to all patients referred to specialist palliative care. Anonymised returned forms are independently analysed to provide monthly reports to the specialist palliative care teams.

Although most voluntary sector organisations had their own individual programmes of user evaluation, the opportunity to participate in a national survey was welcomed.

“We have always used patient satisfaction surveys, but iWGC is a big improvement. The benefits to us are: substantial time savings, the opportunity to compare our results with other organisations, and the reassurance that we are using a properly validated questionnaire. It also offers better anonymity for those patients who want it. The use of iWGC was identified as a strength in our recent CSSIW inspection’. Voluntary Hospice Clinical Matron

iWantGreatCare allows us to evaluate our palliative care services as a nation and offers both patient and carers/families the opportunity to feedback on the effectiveness of service provision in a consistent format across Wales.

The evaluation asks the patient/carer to comment on nine aspects of care:

- **Trust**: Do you trust the staff?
- **Listening**: Do the staff listen to you?
- **Recommend**: Would you recommend the staff?
- **Efficiency**: Are you looked after efficiently?
- **Cleanliness**: How clean is the environment where you are treated?
- **Respect**: Are you treated with dignity and respect?
- **Delays in Care**: Are you looked after promptly?
- **Fears**: How well do staff address your fears?
- **Meeting Need**: How well do staff meet your needs?
Over 1,500 forms have been completed and analysed to date. Feedback suggests that this has been a positive and useful exercise for both patients and professionals alike, providing constructive information on which to shape future services. Feedback is provided individually to each team monthly and each team is able to benchmark themselves against the all-Wales average ratings for that month. Feedback is then monitored by the Palliative Care Implementation Board to provide a mechanism for Wales’ wide positive feedback and lessons to be learnt by service providers.

Example of monthly feedback of a team’s forms, showing the individual domain scores, the corresponding free-text box (on left). Patients are rating against the all Wales average.

Teams are scoring very highly. The average score is 9.6/10 across all services. A total of 54% (n=843) scored 10/10 in every domain, 8% (n=130) had 10/10 in all bar one domain and a further 26% (n=402) of returns had no individual domain scored under 9/10. 34% of returns (n=535) scored over 80 out of a possible 90 total points. Feedback has proved beneficial in validating the investment in services during the last three years. Feedback directly related to investment includes comments on delayed referral to the specialist team, delays in non-specialists (in both primary care and hospital services) responding to the patient’s needs, and the importance of being able to access clinical nurse specialists at weekends.
Scores returned by patient / family

Total score across 9 domains (0-10 per domain)

An Acute Hospital Specialist Palliative Care Team sharing their team’s ‘iWGC’ data report.
**Bridging the Gap:**

**Paediatric Clinical Network**

The sole paediatric palliative medicine consultant, based in South East Wales, has been required to provide advice around Wales. The infrastructure for paediatric palliative care needed to be strengthened to enable the children to be cared for in their own homes when dying.

In each Health Board, funding was provided to release a consultant paediatrician to become the lead for one session a week for paediatric palliative care in that Health Board. This was supported by funding for a specialist paediatric palliative care nurse to work with the Consultant.

Funding was also provided for both the consultant paediatrician and the specialist paediatric palliative care nurse to undertake the paediatric Masters in palliative medicine/palliative care course at Cardiff University.

**Transitional Care**

The feedback from parents revealed the potential chasm that can exist between Paediatric and Adult services for children with life limiting conditions who are surviving into an early adulthood. As survival times improved for those with conditions such as the muscular dystrophies, a pressing need has emerged for improved transition between services. Funding has therefore been used to create a part-time transitional care lead as well as infrastructure support for expert physiotherapy in South Wales for those with muscular dystrophy.
**Bereaved Children**

Hospice services have traditionally provided bereavement support to children who require support when a family member is dying. However, specific dedicated child bereavement services have not been coordinated. Although bereavement fell outside the scope of the Sugar report, the Implementation Board commissioned a piece of work to look at how many bereaved children there are across Wales and what services are available to support them.

In summary, the Fitz report (2010) to the Implementation Board has estimated that there are at least 21,000 young people and children in Wales under the age of 18 who are bereaved of a parent or sibling and at least 37,000 may have been bereaved of a close friend or close family member. Children who are particularly vulnerable, such as ‘looked after’ children, asylum seekers and trafficked children have a particularly high incidence of grief and loss: they have often suffered traumatic bereavement. Wales has led the way with the school counselling strategy, providing 50% of schools with a trained counsellor, but this is not enough. The review revealed that although some very good child bereavement support services exist, they are only able to see a tiny fraction of the number of bereaved children in Wales.

Close links have also been formed with the Child Bereavement Network and the True Colours Trust to try to improve support to children in Wales who are bereaved. A programme of work to help normalise grief is beginning to take shape.

The aim is to have a tiered approach to support, with health, social care and education professionals being able to manage, identify and refer on children to the right level of support.

The Board has therefore recommended that every Local Health Board has in place a dedicated child bereavement coordinator to develop services across their geographical boundaries.
Progress through Research

The establishment of a Wales wide palliative care research network in 2010, made possible by voluntary sector funding, was seen as pivotal to driving up standards of clinical care and to foster enquiry to develop solutions to problems in advancing disease.

Although One Wales funding is directed at core service commitments only, the Palliative Care Implementation Board has sought to support other investment and developments.

During 2010, Marie Curie Cancer Care awarded over £720,000 for the development of a Palliative Care Research Centre at Cardiff University, based within the Wales Cancer Trials Unit to work collaboratively across Wales. Also, the National Institute for Social Care and Health Research (NISCHR) in Wales has supported the development of a palliative care research portfolio, based around four major themes:

1. End of Life Care methodology: The end of life care pathway provides a basis for the potential for cluster randomisation studies.
2. Rehabilitation/Cecelia
3. Patient experience
4. Thrombosis

This work is based from and supported by Wales Cancer Trials Unit with collaborative links with Bristol, Oxford and Marie Curie, and the UK NCRI groups, the Welsh Health Economics Support Service and the Wales Equality and Diversity in Health and Social Care Research and Support Service (WEDHS).

The current focus is on developing three core areas:

- A core academic infrastructure
- The research nurse network in Wales to ensure patients can access existing studies
- Education of palliative care staff in research skills, linked to diploma/MSc activity and through a series of road shows, planned for 2011

The Palliative Care Implementation Board wishes to acknowledge the contribution of all those involved in creating this exciting opportunity for research in Wales.
**Focus on the Last Days of Life**

**Welsh Collaborative Care Pathway for the Last Days of Life**

In 2010 the Welsh Collaborative Care Pathway Project celebrated ten years of progress in establishing a high standard of care for the dying patient in all hospitals, hospices and community settings across Wales. Funding from the Palliative Care Implementation Board has enabled the project to demonstrate that care delivered, using the pathway is significantly improved. During the last ten years, this has resulted in a decrease in the symptom burden experienced by patients.

The Welsh project is unique in collecting anonymised data centrally to enable benchmarking of services and provide a degree of oversight of care. Regular feedback and support sessions are held with users and a yearly review of the documentation carried out. In 2010 a wholesale review of the documentation led to a significantly remodelled version that ensures appropriate use and has brought in the question of possible organ and tissue donation, to support the various initiatives to improve transplant donor rates across Wales.

There has been much interest in the revised version of the Welsh Collaborative Care Pathway for the Last Days of Life both nationally and abroad. It has already been adopted in Hong Kong, strengthening the health care links between the two countries.

**DNACPR**

The Palliative Care Implementation Board recognised a need to avoid distressing situations occurring, where attempts to resuscitate terminally ill patients who were clearly dying were being made. Resuscitation procedures undertaken, very often in the home during emergency calls had caused distress to both family and clinicians. Discussions with the Wales Ambulance Trust resulted in the development of an All Wales DNACPR form (do not attempt cardio pulmonary resuscitation). The DNACPR form is now included within the Welsh Collaborative Care Pathway for the Last Days of Life so clinicians called to the patient’s home in an emergency will be able to treat the patient and their family/carers the appropriate way with dignity and respect.
Ongoing Work

Hospice at Home
Given choice in their preferred place of care, most people wish to end their days in their own home. This is not always possible; the Palliative Care Implementation Board has been working to develop a hospice at home service across Powys and in other rural areas of Wales where transport infrastructure links make access to hospice beds particularly difficult.

The Implementation Board recommended a funding uplift to the per bed financial support for hospices; this has been reflected in a pro rata funding uplift for hospice at home services, where high-quality care can be provided in the patient’s home, often at a lower cost than inpatient care.

Day Care
Day Care services fall outside the scope of Sugar Report recommendations. However, their role in supportive care warrants evaluation. As treatments derived from a strong clinical evidence base can attract NHS funding, the Implementation Board plans to review these services in the coming year to identify how treatments currently delivered in the NHS setting could be provided in the Day Hospice setting.

Wheelchairs
The Board commissioned a report on access to wheelchairs. These revealed unacceptable delays for patients, particularly those with advancing neuromuscular disease, accessing the wheelchairs and other adaptations which they need to allow them to continue to live and function as independently as possible in society. The deficits identified will require urgent work over the coming two years.

Children’s bereavement support
Open discussion about death and dying requires support across many walks of life. Many professionals in all fields are fearful of discussing death with children, so the successful bereavement support will depend on awareness-raising at many levels across Welsh society.

Communication skills training
Ongoing professional development is required across all disciplines to improve communication with patients and with their families over all aspects of end-of-life care. Professionals also need to be empowered to ensure that, however ill a patient is, the patient remains the focus of health and social care and that the health care system responds flexibly to patients’ needs.

Monitoring quality across NHS Wales
Palliative Care criteria relevant to all services have been included in the 2011-12 Quality Framework for Wales. The monitoring of these is a responsibility of the Board, working with others.
Palliative Care Alliance

The Board wishes to formalise its consultation processes with all stakeholders, by bringing them together in an Alliance, to meet annually and to steer the advice to be available to the Minister for future strategic development Palliative Care Alliance Cymru as below:
Death and Dying: Everybody’s Business

Dying Well Matters

The majority of dying patients will receive end of life care from non-specialist teams. These patients will not have the opportunity to provide feedback through the IWantGreatCare evaluation. It was important to the Palliative Care Implementation Board to receive feedback from across the whole health economy about things that went well and things that should have been done differently for all patients with end of life care needs. The views of these patients and families have been sought using the Dying Well Matters programme to inform strategy and service development.

The Dying Well Matters programme in Wales was launched in December 2009, 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 leaves 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 care
- Delays in seeking professional colleagues’ help when teams are unable to offer the full range of services required to support complex patients

Most parts of NHS Wales and their voluntary sector partners provide excellent patient focused end of life care, but the benefits of this can be lost by an encounter with any service that is not working well. The specific issues have informed future programmes of training and education and contributed to the development of Standards in Palliative Care.

And the Board adopts the watchword of Cecily Saunders, founder of the modern hospice:

“There is so much more to be done”