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# Together for Health – Delivering End of Life Care

**A Delivery Plan up to 2016 for NHS Wales  
and its Partners**

The highest standard of care for everyone at the end of life



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## **Ministerial Foreword- Mark Drakeford AM**

### **Minister for Health and Social Services**

Dying is a social matter; how well we care for people who are dying reflects on how we care as a society. Advances in modern medicine and treatment have resulted in a growing population living longer with incurable diseases. Good end of life and palliative care should be available across Wales.

Where death can be expected we must be prepared to have honest and open conversations about the end of life. It should not be a taboo subject. Preparing and planning for the end of life with the involvement of family, carers and professionals is essential to the delivery of high quality care. We must reach into communities to support people, if they wish, to remain in their home or place of care at the end of life.

This plan sets out the Welsh Government's expectations of NHS Wales, working with its partners, in particular the hospice and social care sector, to reduce inequalities in end of life care up to 2016. It sets out how patients and their families will be supported at the end of life, providing high quality care in all settings for people of all ages.

The Palliative Care Implementation Board was established in July 2008 to deliver the recommendations of the Palliative Care Planning Report (Sugar) following its publication by the Welsh Government in 2008. The Report set out recommendations for palliative care provision in Wales, with clear actions up to 2011. Good progress has been made in delivering the actions set out in the Sugar Report. This plan builds on these achievements and is aligned with Government's overall policy on health and health services, as set out in our Programme for Government and Together for Health.

The Programme for Government places a clear responsibility on Local Health Boards and our NHS Trusts, to promote and protect the health of people in Wales and plan and deliver high quality end of life care services.

Whilst the NHS must take a lead, others too need to play their part. There is a very important role for Local Government in working collaboratively with NHS Wales and Third Sector providers to deliver integrated and supportive family centred care.

The individual must be at the centre of end of life care services. In the delivery of high quality services we must listen to ensure the voice of the individual is never lost.

End of Life Care is care for a person – not a patient, or a service user, but a person in the full and rounded sense. The Plan sets out clear ways in which the voice of the individual, supported by those closer to them, is heard and respected at the centre of the services they need.

I wish to record my thanks to all those who have contributed to the development of this plan through the consultation and wider engagement. I am particularly grateful to members of the Implementation Board for their leadership and work in the preparation of this Plan and together we are committed to ensuring Wales has effective end of life care and support available to all patients and their families whenever it is needed.

## **Foreword from David Sissling, Chief Executive of NHS Wales**

I commit Local Health Boards and Trusts, working together with their partners, to plan secure and deliver safe, sustainable, high quality end of life care for their populations.

I will support them in their endeavour and I will hold Local Health Boards to account on the outcomes they deliver for their populations and their contribution to the overall health of the people of Wales.

This End of Life Care Delivery Plan for the NHS together with its partners sets a compelling vision for success. It challenges each organisation to plan and deliver high quality service partnerships. I want to see continuous improvement integrated into everyday working. Our measures for success must focus on public health outcomes, the quality of our service and the individual's experience.

Using Together for Health - Delivering End of Life Care as a framework, my challenge to the NHS is to work effectively with your full range of partners to plan, innovate and, most importantly, to deliver really effective end of life care.

## 1. Introduction

Together for Health - Delivering End of Life Care, provides a framework for action by Local Health Boards, NHS Trusts and Third Sector partners. It sets out the Welsh Government's expectations of the NHS in Wales in delivering high quality end of life care, regardless of diagnosis, circumstance or place of residence in Wales. The plan is split into 6 areas:

- Delivery Theme 1: Supporting Living and Dying Well
- Delivery Theme 2: Detecting and Identifying Patients Early
- Delivery Theme 3: Delivering Fast Effective Care
- Delivery Theme 4: Reducing the Distress of Terminal Illness for Patients and their Families
- Delivery Theme 5: Improving Information
- Delivery Theme 6: Targeting Research

It sets out:

- Delivery aspirations we expect
- Specific priorities for 2013-2016
- Responsibility to develop and deliver actions
- Population outcome indicators and NHS performance measures

Sections 2-8 below set out the context of the plan.

## 2. Strategic Context – why this and why now?

The Welsh Government's *Programme for Government* and its 5 year NHS Plan, *Together for Health*, sets out an ambitious programme for health and healthcare in Wales so that:

- health will be better for everyone
- access and patient experience will be better
- better service safety and quality will improve health outcomes

*Achieving Excellence: The Quality Delivery Plan* for the NHS in Wales for 2012-16, describes a journey to ensure delivery of consistent excellence in service. It outlines actions for quality assurance and improvement. We commit to a quality-driven NHS that provides services which are safe, effective, accessible, affordable and sustainable and come with an excellent user experience.

The Delivery Plan forms part of a suite of delivery plans for service areas and should be read alongside The Cancer Delivery Plan, Stroke Delivery Plan and forthcoming Heart Diseases and Diabetes Delivery Plans.

The end of life is not an issue confined to health services, Social services in particular have a vital role to play. This plan should also be considered alongside Sustainable Social Services: A Framework for Action.

This Delivery Plan sets out what this means for the delivery of measurable excellence in end of life care services.

### **3. Our Vision**

The Programme for Government states the overall population outcomes we want to achieve: better health for all and reduced inequalities in health. Improving access to high quality end of life care for people in Wales will contribute significantly to these outcomes. This outcome and the aspirations set out in this plan are deliberately ambitious; we must aim for the best services possible.

For our population we want:

- People in Wales to have a healthy, realistic approach to dying, planning appropriately for the event
- People dying in Wales to have access to high quality care wherever they live and die whatever their underlying disease or disability, devoid of any prejudice in relation to their personal situation

We will use the following outcome indicators to measure success:

1. % of people dying in place of preference

2. % of people with palliative needs on a primary care practice Palliative Care Register six months prior to death
3. % of people who die in usual place of care
4. % of people in Wales who die intestate

#### **4. Our Drivers**

There are clear reasons for end of life care remaining a top priority in Wales. Everybody is affected by the death of a family member or friend who has gone through a final phase of illness. Not only do people need rapid assessment and the best possible treatment, they also need ongoing support and information about choices when treatment may no longer be effective. The NHS must be able to explain clearly the options and their implications to an individual and their family at the end of life. The NHS in Wales must be committed to taking the lead, working with its partners, to delivering this at every stage of the patient journey.

#### **5. Our Journey so far**

It is clear much has already been achieved in Wales but there is more to do. The Palliative Care Implementation Board has worked with Local Health Boards, Trusts and Third Sector providers, to strengthen existing services. A core requirement for specialist palliative care provision has been established to ensure each Health Board population has adequate access to specialist palliative care (wherever it is provided).

Education programmes for General Practitioners have been developed and educational initiatives were introduced into Nursing Homes. A clinical database has been established. Welsh Quality Markers for service provision have been developed with Health Inspectorate Wales to form the basis of a Peer Review programme.

This work is underpinned by use of feedback collected on a regular basis and reported monthly for each team across Wales. It is complemented by the Dying Well Matters Initiative in which patients and their families are invited to tell their story of their care. This feedback is informing further service developments.

With these foundations in place now is the time to go further and reach out beyond the traditional boundaries of health services. We must reach into communities to support people, if they wish, to remain in their homes or place of care at the end of life. We must support those who work in local communities, in particular in social care, to have the skills to support individuals and their families at the end of life. We must support people to have open and honest conversations about death, it should not be a taboo subject, discussions about preferences and options are essential to supporting individuals at the end of life and reducing distress for the family.

## **6. Working Together**

All of us have a part to play in achieving the ambitions of this plan.

### **The Wales Palliative Care Implementation Board**

The Board will provide strong national leadership to oversee the delivery of the plan. It will be reconstituted to include representation of all those involved in the delivery of end of life care, including ensuring the voice of patients and their families are at the centre of service planning and delivery. The Board will operate in an open and transparent way, publishing minutes, reports and papers. The Board is accountable to the Welsh Government.

The Board will:

- Identify constraints and solutions to delivery where a strategic approach is needed
- Operate at an all Wales level to support Local Health Boards to deliver in a consistent and integrated way across Wales
- Agree how best to measure success, advising on the use of outcome indicators and performance measures
- Scrutinise local delivery plans and assess progress – providing peer challenge of performance and quality
- Facilitate the sharing and implementation of best practice
- Advise the Welsh Government on the allocation of funding

## **NHS Wales and Third Sector Partners**

The NHS is made up of 7 Local Health Boards and 3 NHS Trusts. Local Health Boards are responsible for planning, securing and delivering local services to help people at the end of life receive equitable, planned care appropriate to their need, wherever they reside in Wales. The 7 Local Health Boards in Wales, together with Velindre NHS Trust, work in partnership as the Palliative Care Implementation Board to plan and deliver end of life care.

To plan services effectively for their populations Local Health Boards must build and lead coalitions with Trusts, locality networks, GPs, pharmacists, dentists, opticians, social services and the Third Sector voluntary bodies. Palliative care charities and independent hospices are essential in meeting the needs of people with end of life care needs. These services need to be part of an integrated end of life care service.

Public Health Wales NHS Trust provides Local Health Boards with information and advice to inform service planning. The National Wales Informatics Service (NWIS), supports Local Health Boards in the collecting and reporting of information. This includes the Information System Cymru (CaNISC) palliative care programme where clinical patient information is recorded.

## **Local Government**

Local Government has a vital role to play in supporting communities and individuals to develop a healthy approach to end of life through advanced planning. To promote a co-ordinated approach they need to work with Local Health Boards through Local Service Boards. This work includes the analysis of the evidence base and development of Single Integrated Plans showing how they can contribute to improving health outcomes.

## **People**

People do not choose to develop an incurable condition. Through the gradual ageing process, we will all reach a point where life expectancy is limited. People can

however, choose to minimise risk through lifestyle choices as these can impact on people's health. We all need to take more responsibility for our own health and wellbeing, making an active contribution to minimising risks and harm, which can cost us dear and place an avoidable cost on limited NHS resources.

A healthy approach to dying, planning ahead and informing family and friends of their wishes can result in improved person centred, tailored care at the end of life. Putting affairs in order could begin with simple conversations with friends and families around retirement plans, how you want to be remembered, how you want to be cared for at the end of life, setting out wishes on organ donation, creating memories, saying goodbye and thinking about arranging legal and financial matters.

### **The Welsh Government**

The Welsh Government is responsible for strategic leadership through setting the health outcomes it expects for the people of Wales. It holds NHS Wales to account on how well it delivers the outcomes we want. The lines of accountability are via the Chairs of the Local Health Boards and Trusts to the Minister for Health and Social Services. The Chief Executives of the Local Health Boards and Trusts report to the Chief Executive of the NHS Wales who is also the Director General of the Welsh Government's Department of Health, Social Services and Children. There are regular performance reviews. Progress will be overseen through monitoring the specified levels of performance by 2016 for each of the NHS performance measures. Welsh Government will assure itself Boards are themselves gaining information and assurance of service quality.

## **7. Measuring Success**

The Quality Delivery Plan sets out how we will monitor performance and progress in improving health and health care in Wales. An initial Outcome Framework will be developed during 2013 and will include indicators introduced in this and other delivery plans.

The Quality Delivery Plan places requirements on NHS organisations to monitor a set of quality metrics and report to their Boards and to the public and hence to Welsh

Government, at regular intervals. This End of Life Care Delivery Plan now places a requirement on each organisation to publish an annual report on end of life services for the public of Wales each year to demonstrate progress. The year 2013/14 will therefore be one of transition as we move to this new approach.

The Delivery Plan sets out an initial set of national outcome indicators and NHS performance measures. We recognise the data sets in relation to the indicators and measures may not be in place yet and new data sets may be required. The measures will be refined in discussion with the NHS and partners and a final set of measures and indicators will be produced.

## **8. Local Plans – Local Action**

In response to this End of Life Care Delivery Plan, Local Health Boards are required, together with their partners, to produce and publish a detailed local end of life care delivery plan to identify, monitor and evaluate action needed by when and by whom.

The Local Health Board Executive Leads for End of Life Care will report progress formally to their Boards against milestones in these delivery plans and publish these reports on their websites.

Whilst this plan sets out our expectations of the NHS, the delivery process which will follow is intended to be dynamic and flexible and able to demonstrate real improvement along the way.

## **6.1 Supporting Living and Dying Well**

People in Wales have a healthy realistic approach to dying. They are encouraged to adopt healthy lifestyles, yet are informed and supported to make arrangements in advance for the end of life.

Effective planning for the end of life can result in more efficient care. Individuals should be supported in planning for the end of life with the help of professionals and relatives. Services should be available in an integrated way within a range of community settings. Services should recognise children with a life limiting condition are a distinct group and care needs are often different from those of adults.

### **Delivery Aspirations**

- greater integration between Local Authorities, Third Sector, Social Services and Health Services to support those at the end of life
- appropriate arrangements in place to support those moving between health and social care
- training opportunities for primary care and social care teams to encourage patients to have in place plans for the end of life
- improved communication skills of health and social care professionals to talk to patients and families regarding end of life options
- where appropriate organ donation preferences are included in discussions in line with NICE Guidance
- greater public awareness of the need to have arrangements in place for the end of life, including making a will, addressing their financial matters and making a plan for their wishes at the end of life
- bereavement support is provided within local communities
- patients are supported in their place of care
- greater awareness among paediatricians and other professionals caring for children with life limiting conditions of the need for timely discussion of preferences for care at

and around the time of death

- ensuring for children, where the terminal phase is likely to be long, continuous support and opportunities

## **Specific Priorities 2013-2016**

### **Local Health Boards to:**

- Support training for primary care teams to encourage patients to have in place plans for the end of life
- Deliver training for GPs and Primary Care Professionals to provide care in community settings
- Improve communication skills of health professionals and social care teams to talk to patients regarding end of life plans
- Ensure paediatricians are aware of the Advance and Emergency Care Planning Process and engage with it in a timely manner with individual families
- Put in place lead pharmacists in each LHB to support improvement of medicine management at the end of life
- Support the delivery of training and support for carers

### **Public Health Wales NHS Trust working with Health Boards and Local Government to:**

- Promote public awareness of the need to have arrangements in place for their death, including making a will, addressing their financial matters and a plan for their wishes

### **Population Outcome Indicators**

- % of people who die intestate
- % of people who die in place of preference
- % of people in Wales who die in place of care

### **NHS Performance Measures**

- % of people who have an Advance Care Plan in place
- % Reduction in emergency admissions for palliative care patients

### **6.2 Detecting and identifying patients early**

People with palliative care needs are identified early to enable the best care to be planned in advance

It is important to identify patients with changing care needs towards the end of life at an early stage, through the use of Palliative Care registers and regular multidisciplinary team meetings involving primary and social care. This will ensure care planning is well co-ordinated and a person's individual needs are assessed and met.

### **Delivery Aspirations**

- patient's early identification in last year of life
- professionals recognise patients are entering the palliative phase of illness and communicate with the patient, relatives and colleagues' regarding future care
- increase in Primary care practices holding regular monthly Multi Disciplinary Team Meetings to discuss patients on a palliative care register
- ensuring patients and their families understand their condition, what to look out for and what to do, including when to seek additional help
- patients and families know who is leading their clinical care at all times
- generalist clinical teams know how to access support and advice from specialist palliative care services

- timely transport is available for those patients who need to be moved for their care
- information is available by telephone and on-line to support care at home
- people's views on services are sought regularly and acted on to ensure continuous service improvement.

## **Specific Priorities 2013-16**

### **Local Health Boards to:**

- Work with GP practices to encourage the use of Palliative Care registers for patients, including paediatrics, with less than one year life expectancy and in particular, non-cancer patients
- Promote the benefit of regular multi-disciplinary team meetings to discuss patients on a Palliative Care register
- Encourage professionals to improve their communication and clinical skills to recognise patients entering the palliative phase of illness
- Provide information so generalist teams know how to access support from specialist palliative care services, including paediatricians

### **Population Outcome Indicators**

- % of people who die whilst on a primary care practice Palliative Care Register 6 months prior to death

### **NHS Performance Measures**

- % of practices who have regular review meetings to discuss the needs of patients on the palliative care register
- Time lapse from referral to Specialist Palliative Care to death
- % of people who die within 4 months of having had a DS1500 assessment

### **6.3 Delivering Fast, Effective Care**

People receive fast, effective person centred care in order to maintain quality of life for as long as possible. Patients and their families have their needs identified and met so they feel well supported and informed, able to cope with their illness.

Individuals with end of life care needs require care in a variety of settings - home, hospices, nursing homes, hospitals, specialist centres. Services should be co-ordinated, with communication facilitating smooth transfer of care and information across boundaries. This will include advance planning to ensure appropriate drugs are available out of hours and ensuring out of hours services are aware of all patients who may require end of life care.

Putting the patient at the heart of care planning, will instil trust and confidence in the direction and quality of their care.

### **Delivery Aspirations**

- dignity and respect are maintained at all times
- systems to assure high quality palliative care provision through good communication between all those involved in providing health and social care
- seamless integration of specialist palliative care across NHS and Third sector providers and integration with other specialist and generalist services
- specialist palliative care support to other clinical services available 24 hours a day, 365 days a year, with access to specialist services for patients in whom symptoms are not responding to treatment by generic teams
- specialist palliative care centres of excellence that match or surpass the best and are seamlessly connected with local service providers
- people's clinical and non clinical needs at the end of life are assessed and recorded using an Integrated Care Priorities Approach, with services designed around meeting those needs

- those caring for patients at the end of life have some knowledge of the practices of different faith groups and cultures and access to information and support when required

## **Specific Priorities 2013-16**

### **Local Health Boards to:**

- Plan and deliver high quality evidence based end of life care services through well organised multi disciplinary teams, in line with national guidelines such as The Welsh 'Quality Markers End of Life Care' (2012)
- Ensure effective sharing of information between services
- All NHS and Third Sector provider organisations providing end of life care must participate in relevant National clinical audits, to drive continuous service improvement
- Work through the Palliative Care Implementation Board to plan strategically specialist facilities and community "hospice at home" style provision
- Collaborate with the Palliative Care Implementation Board and Welsh Government to address capital investment needs, such as service redesign of specialist units
- Deliver Peer Review of palliative care
- Establish mechanisms to gather and act upon feedback from individuals and families

### **Population Outcome Indicator**

- % of people in Wales who die in usual place of care

### **NHS Performance Measure**

- Patient satisfaction surveys including data from iWantGreatCare
- % of patients who die with an Integrated Care Priorities Plan in place
- Number of concerns received regarding end of life care

## **6.4 Reducing the Distress of Terminal Illness for the Patient and their Family**

Patients entering the terminal phase of their illness and their families feel well cared for. Symptoms and problems that are likely to arise are addressed appropriately and promptly.

Reducing distress in patients and complicated grief in the bereaved requires the clinical standards provided by all teams to be raised, supported by specialist palliative care services which are available and accessible.

Patients and their families need realistic choices for care together with assurances they will be fulfilled. The access to appropriate support and symptom control must be the same wherever they die - at home, in hospital, in a care home or a hospice.

Those who wish their care and dying to occur at home should be supported in this choice. Inappropriate unplanned admissions arising through inadequate service provision or inappropriate referral should be avoided.

At the end of life, many interventions become inappropriate as they are burdensome to the patient and do not achieve their clinical goal. The recognition of reversible and irreversible conditions in those who are seriously ill is important to ensure appropriate treatment, avoid early death either through under treatment of treatable conditions or through pursuit of inappropriately burdensome interventions.

Good care will promote:

- Appropriate interventions when conditions are likely to respond to treatment
- Choice in place of care during a person's final illness
- Improved support to those bereaved
- Improved confidence of the public that their needs will be addressed at the end of life

## **Delivery Aspirations**

- patients and their families have access to information and support services
- care is planned using an Integrated Priorities Approach
- Strong communication between local and tertiary palliative care teams, and non statutory services such as Children's hospices
- transition processes are in place from children to adult palliative care services
- more people receiving palliative and end of life care have access to support on a 24/7 basis
- specialist palliative care nursing is available 7 days a week
- families facing bereavement particularly those with children are supported in coming to terms with their impending loss, with additional support in bereavement where needed
- people's needs and wishes, and those of their family, are clarified, clearly recorded and are a key guide to care provided
- rapid response to all causes of distress in the patient (physical, emotional, and spiritual) and support to their family and close carers
- careful monitoring of patients with referral to specialist palliative care advice whenever there is no improvement in a short time frame (a standard of 48hrs has been set)
- key information on all patients seen by the specialist palliative care team (adult or paediatric) is recorded on CaNISC and accessible to others who have clinical responsibility for the patient;
- a reduction in patients being admitted unnecessarily to hospital

## **Specific Priorities**

### **Local Health Boards to:**

- Plan, secure and deliver well co-ordinated palliative and end of life care on a 24/7 basis in line with published guidance

- Support all providers who care for dying patients to participate in the All Wales audit of the Integrated Care Priorities documentation
- Have clear funding streams for specialist palliative care services which are above the minimum levels advised by the Palliative Care Implementation Board
- Support participation in regular surveys of the experience of palliative care patients and their families
- Ensure transition arrangements from child to adult palliative care services are in place
- Put in place 24 hours paediatric palliative care telephone advice rota
- Create a patient and families Reference Group to support the work of the PCIB in overseeing the plan
- Ensure CaNISC is accessible and links with other relevant IT systems eg GPs

#### **Population Outcome Indicators**

- % of people in Wales who die intestate
- % of people in Wales who die in usual place of care
- % of People dying in place of preference

#### **NHS Performance Measures**

- % of patients dying with an Integrated Care Plan in place
- Patient satisfaction surveys data including iWantGreatCare

## **6.5 Improving Information**

There are essentially four types of information needs in NHS Wales:

- Patients need information to make decisions about their care and treatment
- Health professionals need information for the clinical management of patients

- Service planners need information on the health needs of their local populations and how well the NHS is operating
- The public, the NHS, the Third Sector and Welsh Government need information on the outcomes that result from NHS care

The Palliative Care Implementation Board has developed clinical quality measures to be incorporated into the CaNISC Palliative Care Module. This has been designed to support Health Boards to monitor the quality of their services.

Local Health Boards and NHS Trusts can use information from a range of sources, such as the Welsh Government and the Office for National Statistics. Public Health Wales NHS Trust, through its Wales Cancer Intelligence and Surveillance Unit, collects and produces information and analysis for Local Health Boards on incidence, mortality and survival. This needs to link better with more real time data on clinical outcomes to support effective clinical care.

### **Delivery Aspirations**

- Information on support and advice is easily accessible for families and carers
- develop CaNISC to keep pace with clinical information needs and technology
- develop processes to ensure high data quality and analysis tools to interrogate collected data
- develop systems to transfer decisions made by multi-disciplinary teams to primary care, secondary care, out of hours providers, the Third Sector and patients
- consider how information and support is passed on to patients to improve their ability to access services and manage their illnesses
- Use 'iWantGreatCare' data to inform service improvement
- develop CaNISC to keep pace with clinical information needs and technology
- develop processes to ensure high data quality and analysis tools to interrogate collected data
- develop systems to transfer decisions made by multi-disciplinary teams to

primary care, secondary care, out of hours providers, the Third Sector and patients

- consider how information and support is passed on to patients to improve their ability to access services and manage their illnesses

### **Specific Priorities 2013-2016**

#### **Local Health Boards to:**

- Regularly review information available to ensure it is targeted to meet the needs of the patients and their families, including those with difficulties in communication or understanding
- Ensure the best possible IT and communication links to give clinical staff fast, safe and secure access to the information needed anywhere in Wales
- Publish transparent information on the performance of NHS and voluntary sector providers including safety, effectiveness and patients' views
- Record and use clinical information for all palliative care patients using CaNISC.
- Each Local Health Board to report performance against specific end of life quality indicators to the Implementation Board annually
- Publish regular and easy to understand information about the effectiveness of end of life care services

#### **Public Health Wales and Velindre NHS Trusts to:**

- Provide Local Health Boards with trend and analysis of mortality, place of death and any relevant information to inform local service planning
- Provide an effective palliative care clinical information infrastructure by developing CaNISC
- Analyse and benchmark information to facilitate and inform Local Health Boards' participation in national clinical audit and peer review
- Roll out CaNISC to a broader range of service providers and explore the integration of CaNISC with other systems

## 6.6 Targeting Research

Research is critical in providing evidence based care. The NHS must respond to the latest research in the planning and delivery of its services. The Marie Curie Palliative Care Research Centre in Wales is playing a vital role in developing a nationally recognised End of Life Research programme in Wales.

We need to ensure patients and their families are aware of the opportunity to participate in research which can lead to better outcomes for patients. The NHS must continue to promote the research base and ensure access to clinical trials, where appropriate.

Patients benefit through the on-going implementation of evidence based best practice. An active research culture in hospitals provides staff with opportunities to develop skills and gain experience of innovative treatments.

### Delivery Aspirations

- Support the continued education of professionals and encourage them to participate and conduct research

### Specific Priorities 2013-14

#### Local Health Boards to:

- Foster a strong culture of research
- Work closely with the National Institute for Social Care & Health Research (NISCHR)
- Work in partnership with cancer research organisations throughout Wales
- Offer all appropriate patients access to a relevant clinical trial
- Actively support the All Wales Integrated Care Priorities audit and research programme
- Support and encourage protected research time for clinically active staff

- Promote the use of key research facilities such as the Marie Curie Research Centre

## HIGH LEVEL ACTIONS TO SUPPORT DELIVERY

Key Action	By Whom	By When
Reconstitute the Palliative Care Implementation Board to include representation of all involved in delivering end of life care	Palliative Care Implementation Board	June 2013
Finalise a set of End of Life Care Outcome Indicators and NHS Performance Measures	Palliative Care Implementation Board together with the NHS	June 2013
Write local delivery plans to ensure significant and systematic progress by 2016 against this Delivery Plan	Each Local Health Board, in liaison with Trusts, Local Government and the third sector to ensure integrated care provision	September 2013
Report formal progress against the local and delivery plans to Boards and Welsh Government	Local Health Boards and Trusts and Implementation Board and the NHS  (reporting format to be developed by Welsh Government and agreed by Implementation Board)	Annually, in March 2014, 2015 and 2016

Publish data on outcome indicators and performance measures on websites	Local Health Boards and Trusts	Annually in March 2014, 2015 and 2016
Review and update delivery plans and milestones	Each Local Health Board, in liaison with Trusts, Local Government and the third sector to ensure integrated care provision	At least annually, with first review by March 2014
Publish annual All Wales report	Local Health Boards Welsh Government and the Palliative Care Implementation Board	Following publication of LHB reports in March 2014 and then annually

## End of Life Delivery Plan, Indicators and Assurance Framework

### Vision

People in Wales to have a healthy, realistic approach to dying, planning appropriately for the event

People dying in Wales to have access to high quality care wherever they live and die whatever their underlying disease or disability, devoid of any prejudice in relation to their personal situation

### Outcome Indicators

- % of people in Wales who die intestate
- % of people in Wales who die in usual place of care
- % of People dying in place of preference
- % of people who die whilst on a primary care practice Palliative Care Register 6 months prior to death

### Delivery theme 1: Supporting Living and Dying Well

#### Overarching Indicators

- % of people in Wales who die intestate
- % of people in Wales who die in place of care
- % of people who dying in place of preference

#### Performance (assurance) Measure

- % of people who have an advance care plan in place
- Reduction in emergency admissions for palliative care patients

### Delivery Theme 2: Detecting and identifying patients early

#### Overarching Indicators

- % of people who die whilst on a primary care practice Palliative Care Register 6 months prior to death

#### Performance (assurance) Measure

- % of practices who have regular review meetings to discuss the needs of patients on the palliative care register
- Time lapse from referral to Specialist Palliative Care to death
- % of people who die within 4 months of having had a DS1500 assessment

### Delivery Theme 3: Delivering fast, effective person centred care

#### Overarching Indicators

- % of people in Wales who die in usual place of care
- % of people who die whilst on a primary care practice Palliative Care Register 6 months prior to death

#### Performance (assurance) Measure

- Patient satisfaction surveys data including- iWantGreatCare
- Number of Concerns received regarding end of life care
- % of patients who die with an Integrated Care Priorities Plan in place

### Delivery Theme 4: Reducing distress in the terminal phase for the patient and their family

#### Overarching Indicator

- % of people in Wales who die intestate
- % of people in Wales who die in usual place of care
- % of People dying in place of preference

#### Performance (Assurance) Measures

- % of patients dying with an Integrated Care Plan in place
- Patient satisfaction surveys data including iWantGreatCare