Section 3 The route to success

Plan

Getting started

As you and your organisation consider and put together a plan to implement this work, you will need to give some thought to the following:

1. Who to involve
2. What you need to do
3. Key enablers
4. Other tools to help
5. How to measure progress.

1. Who to involve

You need to communicate with as many people and in as many ways as possible about this initiative, its ethos and its outcomes.

Wherever possible a clinical champion or executive lead should be identified who can both support the work but also clearly articulate to the team what is expected from them, for example that they commit time and energy to the work and take ownership for the aspects of work in their area.

The clinical champion or executive lead can play an important role in keeping the trust board informed of progress and chairing a steering group, if one is established. As a clinical champion for the work, the executive lead can ensure that the multidisciplinary team work across boundaries. They can also help to overcome or unblock any issues which may arise.

A steering group should be established to engage key stakeholders to make valuable contributions to the work, as well as provide a key focus to drive progress and measure success.

The steering group can also be a useful way of involving commissioners of services from the local health and social care community who will be vital to the sustainability of transformational pathways going forward. The steering group will need to have clear terms of reference; membership and governance arrangements and will need to involve all partners in the implementation process.

Ward leaders are a key group to engage with from the start of the process so that the work is theirs to own and to avoid feelings of isolation from the process and being imposed upon. Through this *Transforming end of life care in acute hospitals: The route to success 'how to' guide*, you are giving them a set of good practice models and supporting tools to help them facilitate the transformational change required.

Individuals and their carers should be actively involved where appropriate in line with local patient and public involvement engagement strategies.

TOP TIP

The Transform start up pack houses a wealth of resources and tools to help you get started. For more information visit: www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care.aspx

TOP TIP

The groups of people in the box below are also key to successful end of life care service improvement and should have representation on the steering group or task and finish groups as appropriate. Use the Change Model or Ambitions document to help you identify key stakeholders.

- Allied health professionals
- Ambulance services
- Clinical Commissioning Groups
- Clinical networks
- Clinical senates
- Community staff
- Hospices
- Hospital chaplains
- Primary care services
- Social care services
- Mental health services
- Public Health England
- Third sector organisations
- Patients, carers and their families.

2. What you need to do

a. Firstly you need to assess your level of organisational readiness to lead the changes that are required to transform end of life care in your organisation. You can do this by working with your clinical champion or executive lead to identify the strategic priorities which align with end of life care, in order to avoid duplication and build on progress already being made.

b. You also need to undertake a baseline assessment of your current end of life care provision. This also needs to include patient experience and insight data, assessing what progress has already been achieved and whether earlier work to raise standards of care is being sustained.

c. With the support of your clinical champion or executive lead, you should agree what resources are available, where in the organisation you should start and governance arrangements, including steering group membership.

d. You should also develop a project plan that seeks to build in spread and sustainability from the outset. Your project plan should have key milestones and where progress is checked, for example whether the first steering group meeting has happened or whether the baseline assessment has been completed. The project plan should outline how your organisation has:
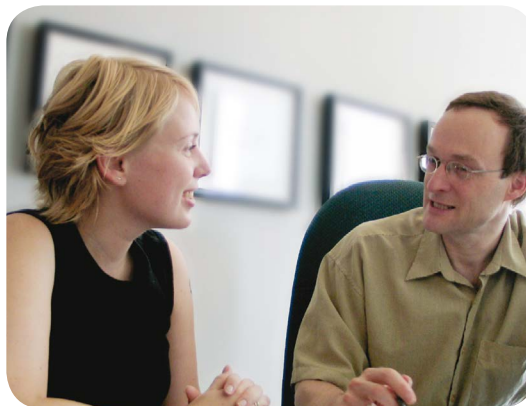

- Defined its strategic goals and how these align with your vision for transforming end of life care[1]
- Aligned this work with current organisational and national strategy
- Geared up the whole organisation to support ambitions
- Signed off the project with trust board and steering group
- Established project governance
- Identified any existing national and local measures that can be integrated into the work programme
- Communicated the plan across the multidisciplinary teams and secured support from key stakeholders

[1] The Productive Ward: Releasing Time to Care™ (NHS Institute for Innovation and Improvement)
www.institute.nhs.uk/quality_and_value/productivity_series/productive_ward.html

- Started to develop an agreed set of local measures to track progress based on the 'how to' guide metrics for wards and trust boards
- Considered the starting point for the work, e.g. a 'showcase ward'
- Have clear roll out and review plans for spread and sustainability over time.

e. The plan should be built on a 'bottom up' approach, however its overall success will depend on clear and visible links to your organisation's strategy, as well as clear and visible leadership and support from the trust board

f. You will need a communications plan and a realistic time frame to ensure you achieve good engagement across the organisation and stakeholders.
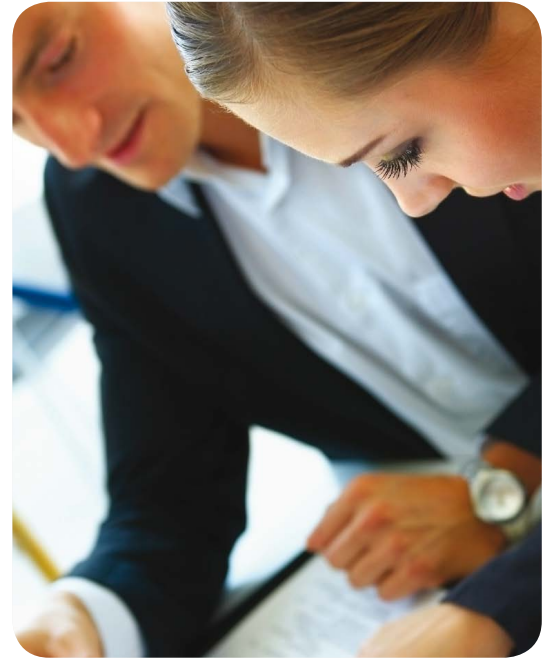
TOP TIP

Use the NHS 6C's to help support the development of a cultutre for compassionate care. These principlas are:

- Courage
- Commitment
- Care
- Compassion
- Competence
- Communication

TOP TIPS

- Do you have the support and leadership at executive level?
- Are the changes you want to make aligned with the strategic priorities of your organisation and wider community?
- Are governance arrangements for the improvement work either planned or in place?
- Have you communication plans in place to ensure everyone is aware of the improvements you plan to undertake?

- Measurement for improvement not judgement is important
- Have you planned to undertake a baseline before you introduce change so you can demonstrate the improvements that you have made ?
- Have you thought about building sustainability in from the outset in the prepare phase?
- Have you got the right people in place and are you enabling them to have local ownership for the change you have planned?

3. Key enablers

The focus is to ensure everyone is treated as an individual, identifying the key enablers that will help you and your organisation achieve high quality care for everyone will be key to your success. Enablers such as Electronic Palliative Care Co-ordination Systems (EPaCCS), Amber care bundle, Advance Care Planning will help you provide high quality care that is well planned,co-ordinated,monitored and responsive to the individual's needs and wishes.

This *Transforming end of life care in acute hospitals: The route to success 'how to' guide* will help you adopt and adapt tried and tested approaches to implementing end of life care - so you can accelerate your progress towards improving the quality and experience of end of life care in your local services.

Key approaches and enablers would include:
- Advance Care Planning (ACP)
- Electronic Palliative Care Co-ordination Systems (EPaCCS)
- Rapid discharge home
- AMBER care bundle
- Priorities for Care
- Large scale change.
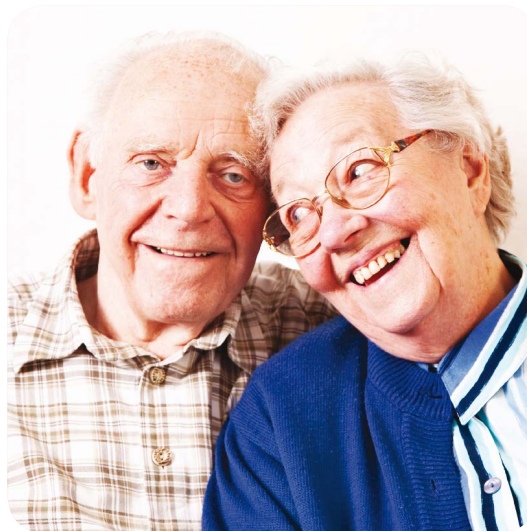
Advance Care Planning (ACP)

Advance Care Planning is a voluntary process of discussion and review to help an individual who has the capacity to anticipate how their condition may affect them in the future.

If the person wishes to they can set on record choices about their care and treatment[2] (known as Advanced Statement) and/or an advance decision to refuse a treatment[3] in specific circumstances.

These choices can then be referred to by those responsible for care and treatment (whether professional staff or family carers) in the event that the person loses capacity to decide once their illness progresses.

Advance Care Planning will involve a series of conversations and reviews in which a person's wishes are explored, identified and then recorded. There should be locally agreed policies about where care planning documentation is kept, including any formalised outcomes of Advance Care Planning.

There should also be systems in place to enable sharing between the health and social care professionals involved in the care and treatment, including out-of-hours providers and ambulance services.

Useful ACP support tools are:

- Preferred priorities for care documentation (NEoLCP) (National PPC Review Team, 2007)
- Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff (NEoLCP, 2011)
- The differences between general care planning and decisions made in advance (NEoLCP, 2010)
- Planning for your future care (revised NHS Improving Quality 2014)
- Holistic common assessment of supportive and palliative care needs for adults requiring end of life care (NEoLCP, 2010)
- e-ELCA End of Life Care for All e-learning, which includes modules on ACP
- Concise Guidance to Good Practice: Advance Care Planning (NEoLCP, 2009)

For health and social care professionals:

- Advance Care Planning e-learning toolkit
  This toolkit contains key information on Advance Care Planning for health and social care professionals – access to the toolkit is free
- Advance Care Planning animation
  This five minute animation gives an overview of Advance Care Planning. Health and social care professionals may find this a useful tool to help explain Advance Care Planning to other professionals and people affected by cancer

[2] www.nhsiq.nhs.uk/media/2455504/supportsheet18_preferred_priorities_of_care_ajr_updated_28_oct.pdf
[3] www.nhsiq.nhs.uk/resource-search/publications/eolc-adrt.aspx
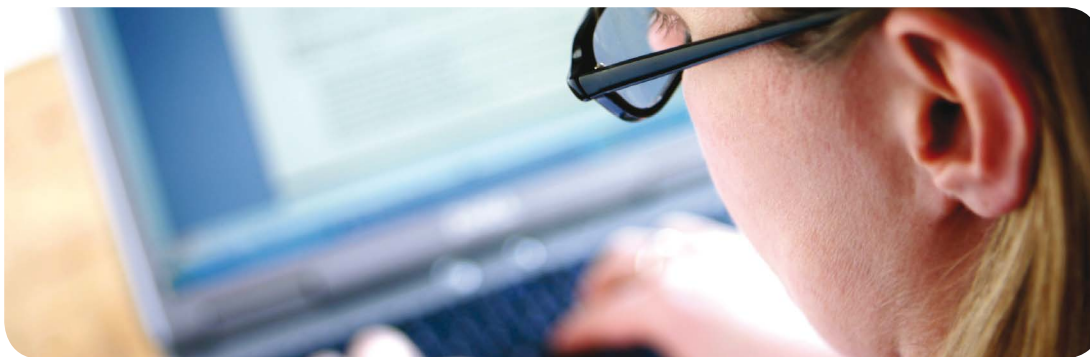
Electronic Palliative Care Co-ordination Systems (EPaCCS)

EPaCCS enable professionals to share key information about end of life wishes, care preferences and key care details for those identified as likely being near the end of their life.

Within governance, the information can be accessed by a range of service providers. The ultimate aim is to improve patient choice and care co-ordination so that patients and families can benefit from active management at the point of care. This facilitates more people to be cared for in the place of their choosing.

EPaCCS have developed from an identified need to improve care co-ordination across multiple agencies recognised as providing end of life care. There is a growing body of documentation about EPaCCS. A good starting point is NHS Improving Quality's 'Making the Case for Change'.

The national information standard - Palliative Care Co-ordination: core content (SCCI1580) - specifies the key data to be held in EPaCCS. It provides full details of the requirement including structure and definitions of the data items. The National End of Life Care Intelligence Network provide a range of resources to support implementation and application of the information standard.

EPaCCS Recommended IT Requirements have been defined through working in partnership with numerous professional bodies. This guidance is offered to help localities meet the national digital agenda for interoperability within their local EPaCCS.

Rapid Discharge Home

Many people who may be in the last twelve months of life would choose a rapid discharge home (or care home). It is important to begin these conversations as early as possible, preferably, with the GP and the patient so that the patient's wishes and preferences are recorded as soon as possible.

For patients in the last days of their lives then the process of rapid discharge home starts with **excellent clear communication**:

• Firstly between patient, family and clinical staff to ensure full recognition and understanding of dying, the possibility and choice of rapid discharge home and the risk of dying en route

• Secondly between hospital teams, pharmacy staff, ambulance services, GPs, out-of-hours medical services, district nursing services, social carers, hospice at home services, equipment loans, accompanied transfer staff (who can give a face to face handover) and others, dependent upon local service configuration.

It also requires each service to recognise this as important and urgent, to make it happen quickly and seamlessly for each patient and family, setting standards for delivering their own element within a specified time, measured in a very small number of hours.

Examples might be agreements for a high dependency (non paramedic) ambulance arriving within two hours, prescription dispensed within two hours, equipment delivered within four hours.

Cross boundary communication and documentation is vital so that **individual plans for care** (which may include an anticipatory management plan for a predictable clinical event e.g. major haemorrhage), involving patient and family, developed in one setting, can be continued in another, and medicines prescribed in hospital can be administered from a completed appropriate **community or care home drug administration order**.

TOP TIP

Remember to ensure written communication with primary care services, for example communicating discharge summaries with an individual's GP.

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Appropriate plans for all predictable events need to be in place:

- **Cross boundary resuscitation plan** - if cardiopulmonary resuscitation is not to be attempted then a cross boundary order recognised by the ambulance service and community services needs to be in place
- **Death in transit plan** - if the patient should die en route - do the family wish them to continue home into their own bed or be brought back to A&E?
- **Death certification plan** - outlining which doctor is in a position to certify the death if the patient should die before being seen by their own GP.

Ward staff should telephone the GP and district nurse as the patient leaves the ward so that they are ready to receive them at home and make that initial assessment visit quickly to provide care and support for patient and family, and out-of-hours services should be faxed with information or **Electronic Palliative Care Co-ordination Systems** used to ensure good co-ordination of care 24/7.

Once a local process is established, and frontline staff become confident in offering a Rapid Discharge Home (or care home) to patients, then the number of patients and families who take up the offer is likely to increase. In one district general hospital for example, 1 in 4 of all patients who are dying in hospital are offered Rapid Discharge Home (or care home); 2 in 5 take up the offer, resulting in 1 in 10 of all those dying in hospital being successfully transferred.

Approximately 1 in 100 transfer attempts fail due to rapid deterioration in condition or delays in the process. Those who are transferred and die, have a median lifespan of four days, whilst 5% improve, require a change of care plan and live several months. For most of these people we have only one chance to get it right first time, there is no rehearsal!

Managing patients whose recovery is uncertain: the AMBER care bundle and treatment escalation plans

The AMBER care bundle is a simple approach used in hospitals for patients who are acutely unwell when clinicians are uncertain whether a patient will recover in part due to underlying chronic conditions or frailty. It supports the proactive management of these types of situations that may be dynamic and changing.

The approach encourages staff, patients and families to continue with treatment in the hope of a recovery, while talking openly about people's wishes and putting plans in place should the worst happen. It consists of four elements:

- Talking to the person and their family to let them know that the healthcare team has concerns about their condition, and to establish their preferences and wishes
- Deciding together how the person will be cared for should their condition get worse
- Documenting a medical plan
- Agreeing these plans with all of the clinical team looking after the person.

The AMBER acronym stands for:

- **A**ssessment
- **M**anagement
- **B**est practice
- **E**ngagement of individuals and carers
- For people whose **R**ecovery is uncertain

Emerging evidence suggests:

- Improved decision making
- A positive impact on multi-professional team communication and working
- Increased nurses' confidence about when to approach medical colleagues to discuss treatment plans
- People being treated with greater dignity and respect
- Greater clarity around preferences and plans about how these can be met.

More information on the AMBER care bundle can be found at:
www.ambercarebundle.org

CASE STUDIES
Worcestershire Acute Hospitals NHS Trust
Building on Board support, education and training and CQUINs to sustain end of life care improvement.

Derby Hospitals NHS Foundation Trust
A measurable impact for patients whose recovery is uncertain.

The person's condition is then monitored closely and followed up on a daily basis to record and respond to any changes and address any concerns that they or their family may have.
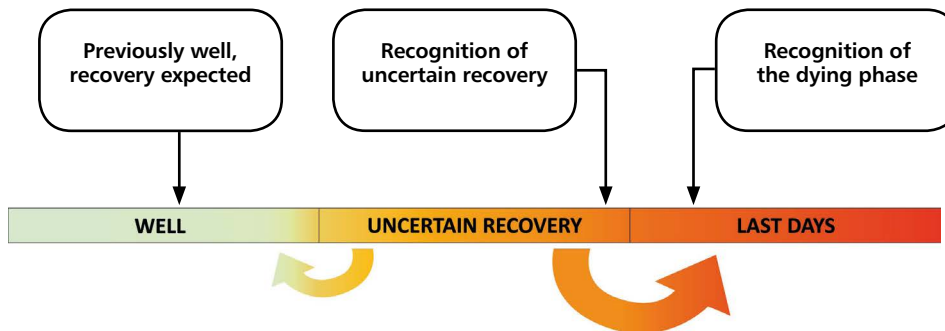
The AMBER care bundle contributes to people being treated with dignity and respect and enables them to receive consistent information from their healthcare team. It helps people and their carers to be fully involved in making decisions and knowing what is happening with their care.

It complements Treatment Escalation Plans (TEP) or similar approaches if these are in use within the hospital trust and in the wider health economy. These set out aspects of medical planning in the event of a patient deteriorating and their Do Not Attempt Cardio Pulmonary Resuscitation Status. Treatment Escalation Plans should also be developed in consultation with patients and those important to them.

If a patient's recovery becomes uncertain, any pre-existing TEP and advance care plans should be reviewed, considered, followed or adjusted as necessary with patients and those important to them.

Underpinning all these approaches is the principle of shared decision-making with patients, involving those important to them as appropriate and offering the necessary support.

Patients whose recovery is uncertain

| Previously well, recovery expected | Recognition of uncertain recovery | Recognition of the dying phase |

| WELL | UNCERTAIN RECOVERY | LAST DAYS |

Priorities for Care of the Dying Person

Priorities for the care of the dying person:

- The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed
- Sensitive communication takes place between staff and the dying person and those identified as important to them
- The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
- An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

The Leadership Alliance for the Care of Dying People has published a new approach to caring for dying people in the last few days and hours of life, that focuses on the needs and wishes of the dying person and those closest to them, in both the planning and delivery of care wherever that may be.
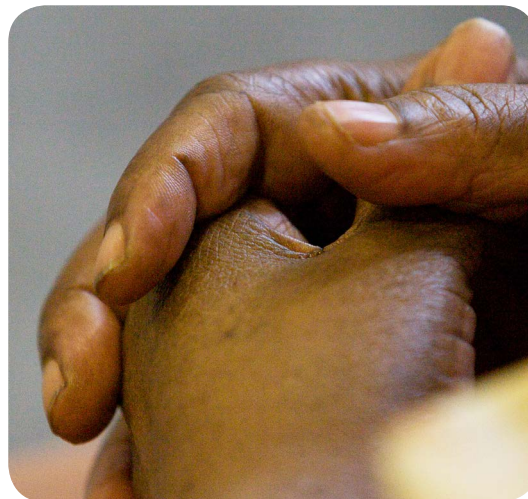
One Chance to get it right - Published June 2014 by the Leadership Alliance for the Care of Dying People
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

4. Other tools to help

You may have preferred approaches and tools within your orginasation that you can use to establish your baseline or starting point. You can also use the tools provided in *The Productive Ward* – to help you do this.

There may also be national or local strategic measures already being reported, including Five Year Forward View priorities and The Forward View into action: planning for 2015/16 that you can use as well. In addition, as part of your planning, you may also wish to reference the Actions for End of Life Care: 2014–16 and the Ambitions for Palliative and End of Life Care.

You can incorporate these into your baseline so that you can ensure that you are measuring what is important, avoiding duplication and establishing a robust baseline which will allow you to report progress with confidence.

Look at what you are already measuring and collecting, involve your executive board and information team to find out what data you collect so that you can build on this.

TOP TIPS

Measuring experience of care in end of life care:
www.nhsiq.nhs.uk/media/2642618/eolc_measuring_experience_of_care.pdf

An overview of Local Measurement: transforming end of life care in acute hospitals programme:
www.nhsiq.nhs.uk/media/2642623/factsheet3_eolc_measurement_analysis.pdf

5. How to measure progress

Measures can be a great asset to you and your organisation in demonstrating whether or not the improvements you have made are working and whether you are making progress towards your strategic or team goals.

The emphasis is on measurement for improvement, not judgement. This is important because many staff get fed up with measures which are either poorly designed or inappropriately used after being set up as performance targets and not improvement goals.

Using measurement to track your progress will lead your team to develop, implement and frequently review a set of measures that are right for you. Measurement can help you move decisions away from opinion and towards facts. We need facts to track our performance over time, help us solve our own challenges and give us better control of our services.

Once you have identified what your organisation and team are currently measuring as part of establishing your baseline, you can make a decision about building these local or national measures into the set of measures you are designing to track the improvements you are planning to introduce.
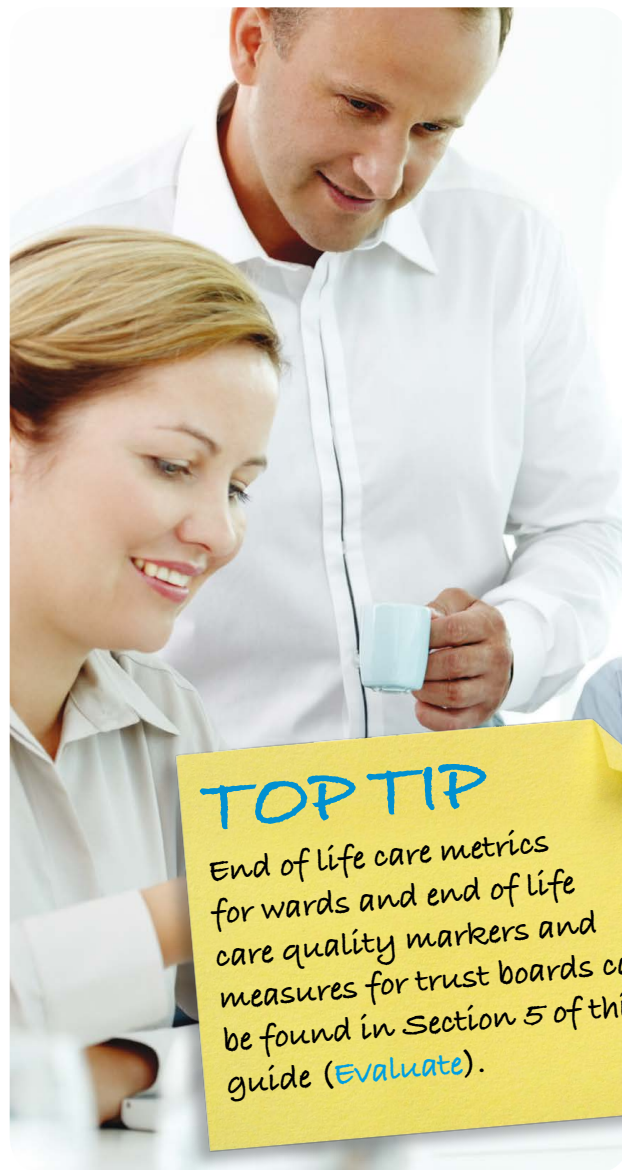
TOP TIP

End of life care metrics for wards and end of life care quality markers and measures for trust boards can be found in Section 5 of this guide (Evaluate).

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When thinking about communicating and developing measures you may like to consider:

- Involving as many staff as possible from the outset as to what data and measures are currently being collected
- Getting opinions from staff, individuals and carers as to what they would like the measures to tell them so that you can establish what is important
- Making sure you communicate that measurement is not an end in itself but a way of raising standards of care
- Having a clear process for developing measures and collecting data along with how you will publicise and present the data. The *Productive Ward* uses a 'knowing how you are doing' board which you can link to or apply with this area of work
- Monitoring progress but most importantly evaluating and acting upon the information your data is showing
- Sharing data with your team, trust board, steering group and key partners.

TOP TIP

Keeping measurement simple, accessible and highly visible will be more motivating for staff than if you design a system with a few senior people in a room and then try to impose these on your team.