

Transforming end of life
care in acute hospitals
The route to success 'how to' guide
(Revised December 2015)



Directorate

Medical
Nursing
Finance

Commissioning Operations
Trans. and Corp. Ops

Patients and Information
Commissioning Strategy

Publications Gateway Reference: 04318

Document Purpose	Other (see Description)
Document Name	Transforming end of life care in acute hospitals: The route to success 'how to' guide
Author	NHS England
Publication Date	December 2015
Target Audience	Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of Nursing, Local Authority CEs, Director of Adult SSs, NHS Trust Board Chairs, NHS England Regional Directors, Allied Health Professionals, Communications Leads, Emergency Care Leads, NHS Trust CEs
Additional Circulation List	
Description	This e-publication supports NHS England's Action for End of Life Care 2014–16. It is part of an existing suite of documents that set out a wider ambition to develop a vision for end of life care beyond 2015.
Cross Reference	
Superseded Docs (if applicable)	Transforming end of life care in acute hospitals: The route to success 'how to' guide (2012)
Action Required	N/A



Timing/Deadlines
(if applicable) N/A

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Document Status

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The route to success
Introduction

Foreword

Some years ago I nursed and cared for my daughter who had breast cancer. Wanting and needing to provide the best possible care for her I worked hard to ensure that this would happen. However due to fear and lack of knowledge, at the very end of her journey I had to call 999 which resulted in an emergency admission.

The ambulance took four hours to arrive and my daughter died in a busy accident and emergency department on a Friday evening. This had a profound and devastating effect on me, leaving me with a heavy burden of guilt even to this day.

Far more recently I was able to stay beside my mother-in-law in the hospital during her last days. The palliative care which she received was wonderful. I was able to assist with some of her care and she was treated with dignity and respect. I feel that I am able to look back without any guilt about her death knowing that it was almost as good as it could have been.

For the sake of the person dying and their carers, let us work towards a system of which we can all be proud, thus relieving families of unnecessary anxiety and guilt.



Roberta Lovick
User carer representative





Foreword

Our first national strategy for end of life care in England, published in 2008, has succeeded in reversing the trend of increasing the proportion of deaths taking place in hospital. Although that significant achievement must be appreciated, the reality is that many people will continue to die in hospitals, sometimes by their own choice, sometimes by necessity of the circumstances leading up to their death. As importantly, many people will need to spend a proportion of their last years, months and weeks of life in hospital because of care and treatment that they need, and wish, to receive. We owe it to them, and those important to them, to make that experience as good as we possibly can whilst they are there.

The route to success in end of life care – achieving quality in acute hospitals was published in 2010 as the first step in a national improvement programme. Then in 2012, the original *Transforming end of life care in acute hospitals: The route to success 'how to' guide* was published as a result of a collaboration between the National End of Life Care Programme and the NHS Institute for Innovation and Improvement. The first wave of 25 hospital trusts led the implementation in 2012, followed by a second wave of 51 hospital trusts, of the 'Transforming end of life care in acute hospitals' programme, commonly known as '*the Transform programme*'.

The publication of this version of the *Transforming end of life care in acute hospitals: The route to success 'how to' guide* marks another significant milestone in this journey. Commissioned by NHS England, the guide's revision has been led by NHS Improving Quality, with contributions from The National Council for Palliative Care, Macmillan Cancer Support and NHS Trust Development Authority, as an early component of our new partnership for improving end of life care in acute hospitals. This provides practical advice and support for front-line clinicians and leaders for the work required to transform end of life care in acute hospitals. I would strongly urge you all to use it to its fullest potential and encourage those who have not yet signed up to this commitment to read it too.

This is a good example of putting into action the recently published *'Ambitions for Palliative and End of Life Care: A national framework for local action: 2015-2020'*. There are six ambitions in the framework: each person is seen as an individual; each person has fair access to care; maximising comfort and wellbeing; care is coordinated; staff are prepared to care; communities are prepared to help. Like the NHS's Five Year Forward View, a fundamental principle of the Ambitions framework is that significant progress in end of life care can only be made and sustained through collaborative and cooperative efforts between people who are part of statutory bodies, voluntary organisations and community groups. It has to be 'everybody's business' and nowhere is this more true than in acute hospitals where every contact, between staff and those they care for, has the potential to make a lasting impact, good or bad. We all need to rise to the challenge of achieving personalised care, treatment and support for the individual within a fast-paced busy acute environment. We must make the experience of care in hospitals as good as it can possibly be for all those who need to be there, especially for those in the last years, months, weeks and days of their life, and those important to them, as well as the staff who work and provide care and support for people in these environments. This must happen in parallel with efforts to improve the conditions and care for people outside hospitals too, so that we do not create, or perpetuate, an artificial divide between hospital and out-of-hospital in terms of quality of care that people can expect to experience.



Professor Bee Wee

National Clinical Director for End of Life Care,
NHS England

Introduction

The Department of Health's *End of Life Care Strategy* (2008)¹ was an important turning point for improving end of life care provision in acute hospitals given that more than half of all deaths occur there.

As well as ensuring that those who die in hospital have a 'good death', the strategy called for improved discharge arrangements and better co-ordination with a range of community and social care services so that more people can die at home if that is their preferred choice.

The route to success in end of life care – achieving quality in acute hospitals (2010) highlighted best practice models developed by acute hospital trusts and supported by The National End of Life Care Programme (now part of NHS Improving Quality). It provided a comprehensive framework to enable acute hospitals to deliver high quality person centred care at the end of life.

This revised *Transforming end of life care in acute hospitals: The route to success 'how to' guide* builds on that overarching framework as well as:

- [NICE guideline on care of dying adults in the last days of life](#)
- [Actions for End of Life Care 2014/16](#) NHS England
- [One Chance to Get it Right](#) the Leadership Alliance for the Care of Dying People June 2014
- [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#)

It also draws on the valuable learning from The Productive Ward Releasing Time to Care programme² originally developed by the NHS Institute for Innovation and Improvement [NHS Improving Quality] helps wards focus on improving their processes and environments to help nurses and other staff spend more time giving direct care to patients.

¹ <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

² www.institute.nhs.uk/quality_and_value/productivity_series/productive_ward.html

Throughout this guide, you will be encouraged to use existing models and practical tools already identified as examples of good practice. They can help you achieve the improvements you wish to prioritise locally to improve the quality of end of life care for your patients and their families. The five key enablers outlined below will greatly assist you towards this aim.

- Advance Care Planning (ACP)
- Electronic Palliative Care Co-ordination Systems (EPaCCS) formerly known as end of life care locality registers
- AMBER care bundle
- Rapid Discharge Home
- Priorities of Care from 'One Chance to Get it Right'.

Ensuring quality of care and putting people's needs at the heart of the healthcare system requires a workforce that is equipped with the right knowledge, skills, competences, attitudes and behaviours.

Education, training and workforce development are essential elements that require embedding as core requirements in corporate governance frameworks to enable the achievement of the aims of the *Transforming end of life care in acute hospitals: The route to success 'how to' guide*.

The Productive Ward Releasing Time to Care³ is a proven approach to engage staff and also to build competence and confidence amongst staff so they can lead improvements in care for themselves. Utilising the principles of continuous improvement within The Productive Ward will help organisations and their staff reshape how they work with each other, with patients and their families and with other key partners for example social care. The Productive Ward six step approach illustrated in Figure 1 overleaf will help you achieve this.

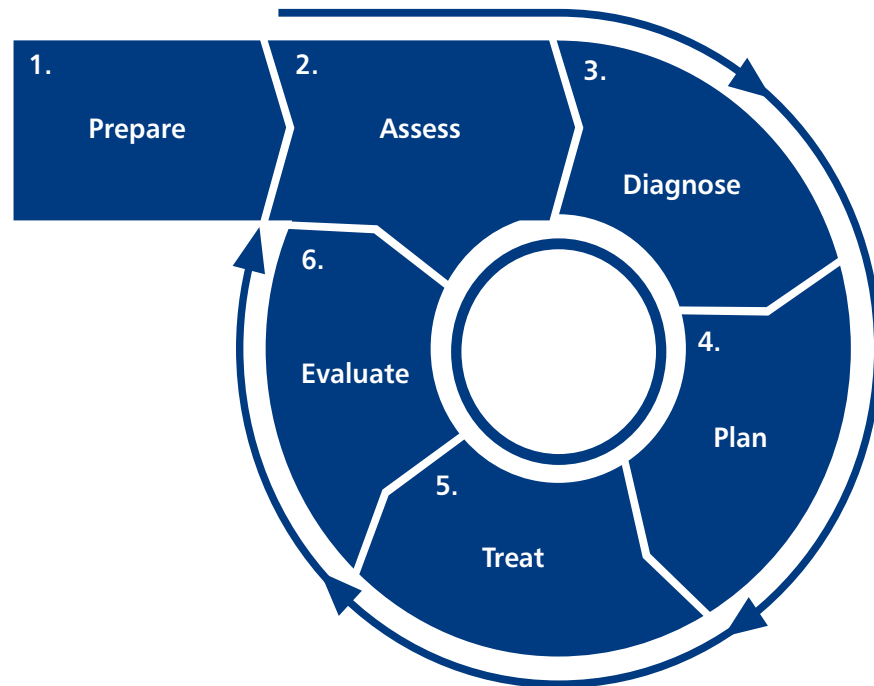
The recently published [Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020](#) will also help you build the momentum for working together locally.

³ www.institute.nhs.uk/images/documents/Quality_and_value/Productive_Ward/PW%20review%20full%20report.pdf



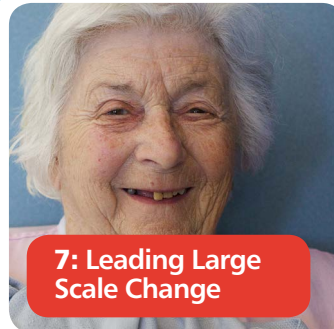
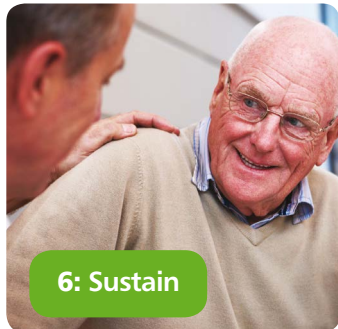
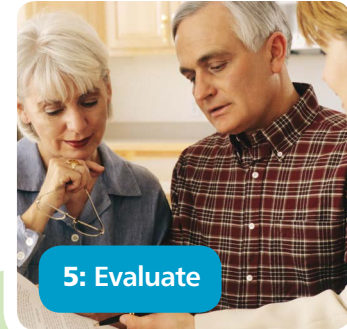
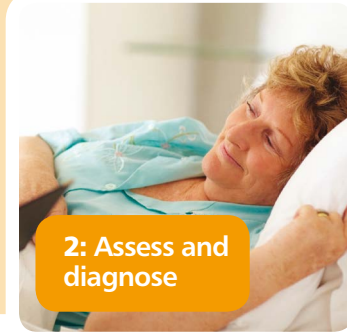
Figure 1:

Six step continuous improvement diagram from The Productive Ward: Releasing Time to Care™ (©NHS Improving Quality).




Introduction

This guide contains individual sections that can be worked on in the order of your choosing, dependent upon your individual hospital and its current end of life care provisions. These include:



The route to success 'how to' guide



A photograph of two women sitting and talking. The woman on the left is wearing a light green top and has long dark hair. The woman on the right is wearing a pink sweater, glasses, and has long dark hair. They are in a professional or educational setting. A pink square graphic is in the top right corner.

Section 1 The route to success

Prepare

What does good look like?

Making good quality accessible end of life care a priority requires collaboration and cooperation to create the climate for change to bring about the improvements we all want to see. Professionals, local leaders within the health and care system and communities working together, collectively and differently is vital to designing new ways of working to achieve:

- Getting care as good as it can be wherever the person is - at all stages
- Care that matches the person's preferences as closely as possible and meets needs as far as possible
- Staff who have confidence to bring these skills into other parts of care
- Reducing the inequality gap
- Everybody feels responsible for playing a positive part in end of life care.

The framework for action developed by the National Palliative and End of Life Care Partnership [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#) is aimed at local health and social care and community leaders. It builds on the [Department of Health's 2008 Strategy for End of Life Care](#) and responds to an increased emphasis on local decision making in the delivery of palliative and end of life care services since the introduction of the Health and Social Care Act 2012.

The six 'ambitions' within the framework are principles for how care for those nearing death should be delivered at local level (see the illustrations on the following three pages for further details).

- 1. Each person is seen as an individual**
- 2. Each person gets fair access to care**
- 3. Maximising comfort and wellbeing**
- 4. Care is coordinated**
- 5. All staff are prepared to care**
- 6. Each community is prepared to help.**

As well as meeting the needs of the individual being cared for, good end of life care would include giving care and support to families, friends, carers and all those who are important to the dying person. It should also include good bereavement and pre-bereavement care.

This section of the *Transforming end of life care in acute hospitals: The route to success 'how to' guide* introduces you to some models which may be helpful in the **Prepare** phase as you seek to engage your local stakeholders and formulate your plans to achieve improvement locally for the benefit of patients and their families.



The six ambitions for palliative and end of life care

- 01 Each person is seen as an individual**
I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.
- 02 Each person gets fair access to care**
I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.
- 03 Maximising comfort and wellbeing**
My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.
- 04 Care is coordinated**
I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.
- 05 All staff are prepared to care**
Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.
- 06 Each community is prepared to help**
I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

The National Palliative and End of Life Care Partnership

<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

The foundations for the ambitions



The National Palliative and End of Life Care Partnership

<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>



The foundations for the ambitions

Personalised care planning

Everybody approaching the end of their life should be offered the chance to create a personalised care plan. Opportunities for informed discussion and planning should be universal. Such conversations must be ongoing with options regularly reviewed.

Education and training

It is vital that every locality and every profession has a framework for their education, training and continuing professional development to achieve and maintain competence and allow expertise and professionalism to flourish.

Shared records

To ensure the plan can guide a person centred approach it has to be available to the person and, with their consent, be shared with all those who may be involved in their care.

24/7 access

When we talk about end of life care we have to talk about access to 24/7 services as needed, as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for 'opening hours'.

Evidence and information

Comprehensive and robust data are necessary to measure the extent to which the outcomes that matter to the person are being achieved. This, alongside strengthening the evidence-base, will help to drive service improvements.

Co-design

End of life care is best designed in collaboration with people who have personal and professional experience of care needs as people die.

Involving, supporting and caring for those important to the dying person

Families, friends, carers and those important to the dying person must be offered care and support. They may be an important part of the person's caring team, if they and the dying person wish them to be regarded in that way. They are also individuals who are facing loss and grief themselves.

Leadership

The leadership of Health and Wellbeing Boards, CCGs and Local Authorities are needed to create the circumstances necessary for action. Clinical leadership must be at the heart of individual service providers.

The National Palliative and End of Life Care Partnership

<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

End of Life Care - House of Care Model



As end of life approaches, individuals and those close to them need to be able to access high quality care that is compassionate, competent and respectful. For this to happen health and social care staff need to make sure they deliver the right person centred care 'the first time, every time.'

[The End of Life Care - House of Care framework](#) describes four key interdependent components that, if implemented together, offer the greatest opportunity for achieving person centred, coordinated care for people approaching the end of their life and those

important to them. Underpinning all four components is personalised care planning where people at or nearing end of life and those closest to them, and professionals work together using a collaborative process of shared decision-making to agree goals, identify support needs, develop and implement action plans, and monitor progress.

The framework is set in the broader context of the community and provides opportunities for organisations to improve the way they deliver care and ensure patients and those close to them have the best experience possible.



Preparation

The NHS Change Model

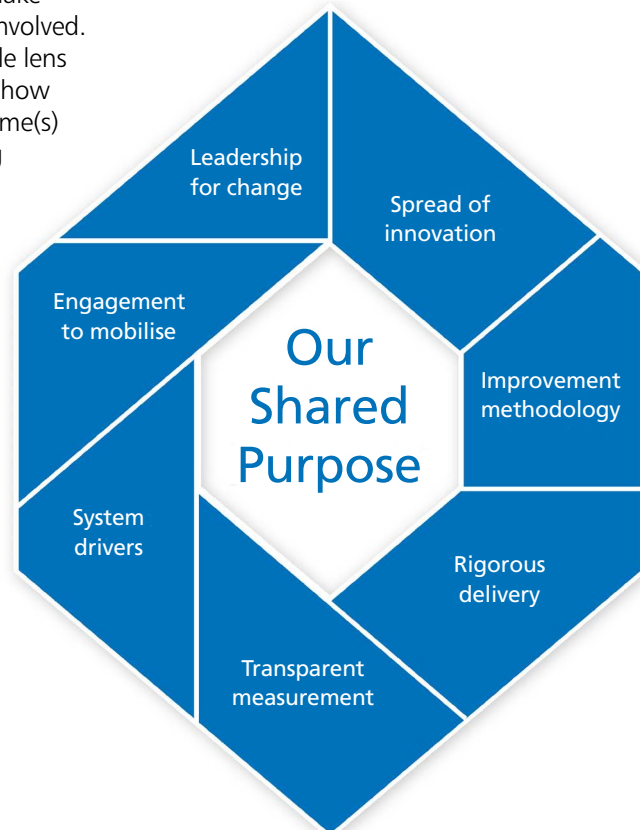
This model provides a useful organising framework for sustainable change and transformation that delivers real benefits for patients and the public. It has been created to support the NHS to adopt a shared approach to leading change and transformation and brings together what we know helps make change happen and who needs to be involved.

The Change Model provides a valuable lens that enables a better understanding of how to create an environment and programme(s) which can make change happen. Using all of the eight components together in equal measure will increase your chances of making change successful.

The eight components are:

- **Our shared purpose**
- **Leadership for change**
- **Spread of innovation**
- **Improvement methodology**
- **Rigorous delivery**
- **Transparent measurement**
- **System drivers**
- **Engagement to mobilise.**

See more at: www.nhs.uk/capacity-capability/nhs-change-model.aspx#sthash.0NY2BUQd.dpuf



Our shared purpose

A clear sense of shared purpose at every level, individuals and organisations, is essential to any successful change. Organisations whose communities are strong, passionate and committed to delivering improvement and outcomes, create shared purpose as a common thread. Shared purpose connects us with our commitment and contribution to our core values - the things that bring us into the NHS and care settings to deliver outcomes that matter to local communities, beyond just what we do as individuals, teams or organisations. We need to know not just what problems we are trying to solve and why it matters, but what our vision is for the future and why that future matters.

Investing in exploring the collective shared purpose at the start of your local improvement programme is central to creating the conditions that foster a climate for leading change, and requires commissioners, providers, voluntary and third sector organisations and people who use services to act together in the interests of patients where the quality of care is as important as the quality of treatment.

Acting together means something when it is connected to purpose, connecting people to the change in a very open way. Our values, which sometimes get eclipsed by structures and hierarchy, unite us to collectively work together to take action on what we hold in common to sustain the improvement programme, to deliver the vision, outcomes



and goals developed through the collective shared purpose. Shared purpose needs to be developed at different levels in the change process connecting back to the overall improvement we want to see. In reconnecting with our shared purpose the pull and push for delivering and adopting improvement is strengthened.



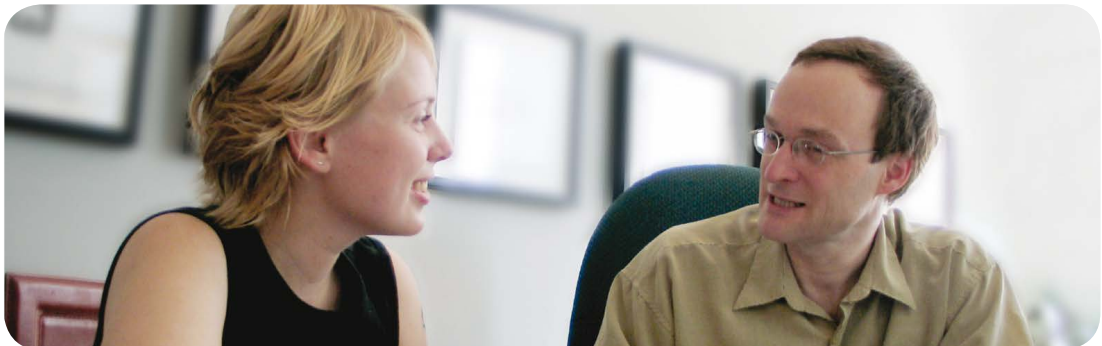
As part of your preparation for implementing *Transforming end of life care in acute hospitals: The route to success 'how to' guide* you will need to think about the following:

1. Why do it?

Currently almost half of all deaths (47%) take place in hospital ([National End of Life Care Intelligence Network, 2015](#)). Nearly 30% of all hospital beds are occupied by someone in their last year of life. ([Prevalent cohort study D. Clark et al 2014](#)) The majority of deaths occur following a period of chronic illness such as respiratory disease, heart disease or cancer. Almost 500,000 people die each year in England, two thirds of whom are 75 years or older. With an ageing population, the number of deaths is set to increase by 17% between 2012 and 2030 ([Local Preferences and Place of Death in Regions within England 2010](#) National End of Life Care Intelligence Network (2011).

Improved delivery outcomes should:

- Improve the experience and quality of care received
- Enable people to die in the place of their choice
- Reduce the number of inappropriate interventions
- Manage and reduce unplanned hospital admissions as well as length of stay
- Improve staff morale and staff retention
- Develop a skilled workforce
- Result in fewer complaints and improved reputation for the trust.
- Allow the trust to manage its resources effectively.





2. Who is it aimed at?

A wealth of reports focussed on quality at end of life have highlighted the variable standards of provision across wards and organisations as well as uncoordinated services for end of life ([More Care, Less Pathway A review of the Liverpool Care Pathway 2013](#); [Dying without Dignity: Investigations by the Parliamentary and Health Service Ombudsman](#) into complaints about end of life; [End of Life Care House of Commons Health Committee report 2015](#)).

In order to support implementation of *Transforming end of life care in acute hospitals: The route to success 'how to' guide* in practice and to accelerate tried and tested models, this guide is for the various combinations of multidisciplinary teams who are responsible for service development, commissioning and practice educators. It is also intended for front line staff who care for individuals at the end of life. While not exhaustive, this includes:

- Allied health professionals
- Bereavement staff
- Board directors
- Community and voluntary sector organisations and groups
- Directorate managers
- Education commissioners
- Generalist hospital clinicians
- Hospital chaplains
- Mortuary staff
- Nurses
- Primary, community and social care service providers
- Service commissioners
- Specialist palliative care teams
- Support staff
- Volunteers.



3. What is your starting point?

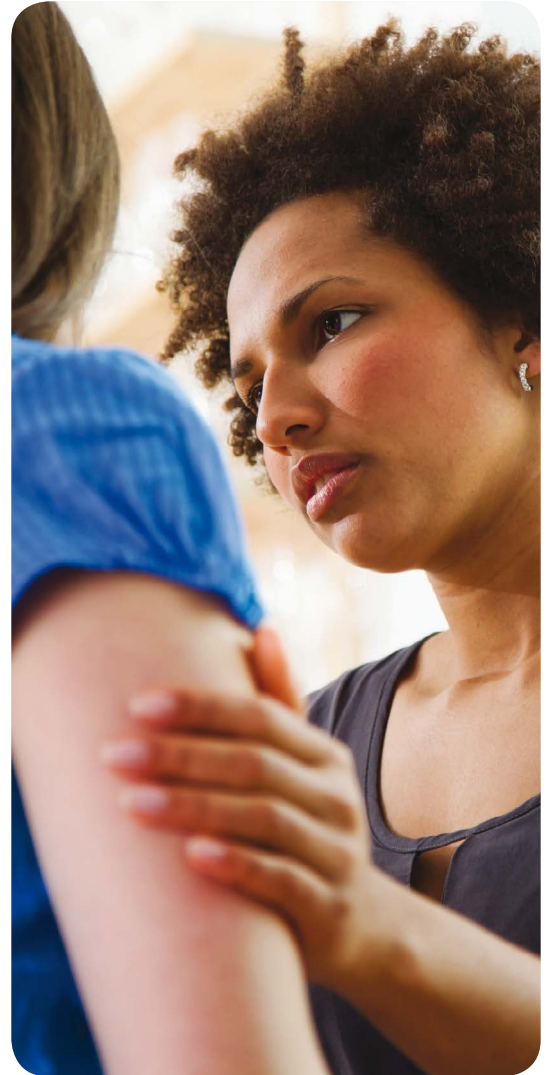
Knowing how your ward and organisation are doing will allow you to scope what is needed for improvement. Asking the following questions will help:


- Do you know how good you are?
- Do you know where you stand relative to your peers?
- Can you identify variations between you and your peers and possible reasons for it?
- Can you monitor your rate of improvement over time?

[Section 2](#) of this guide will show you how to assess and diagnose to help answer these questions.

TOP TIP

Build on what you've already got. Your hospital will be doing some things really well. Find out what they are and start from there. Comparing your performance locally and nationally will also help.



A photograph of two elderly women with short blonde hair looking intently at a tablet computer. The woman on the left is wearing a white top and a silver necklace, while the woman on the right is wearing a grey cardigan over a light-colored top and glasses. They are both focused on the screen of the tablet.

TOP TIP

Use The Productive Ward six step approach to identify the level of organisational readiness for change including what you are already doing well and build on this as part of the 'prepare' phase.

