

Inspiring Improvement in End of Life Care

Dr Ben Lobo

Death is life's greatest change agent

3 Questions

- **What care do we want and expect?**
- **What care don't we want and need to change?**
- **How will we make and measure improvements?**

Focus

- **More Care, Less Pathway**
- **Leadership Alliance for the Care of Dying People**
 - **Understanding and acting on 5 principles and the 44 recommendations**
 - **One chance to get it right**
 - **Priorities of Care**
- **National Audit Care of the Dying 13-14**
- **Being a Critical Friend - Quality Improvement**
- **Preparation for Group work**

Proposal- End of Life care

- Everyone's business
- Part of the business
- All care is built from common and basic parts
- Care starts and finishes with the patient
(in their front room and not the board room)
- Create a sense of urgency
- Get organised and define *your priorities for change*
- Build a collaborative (around the patient) that is focussed on
 - specific on outcomes
 - that are measureable
 - supported by simple QI techniques
- Moral Test

**MORE CARE,
LESS PATHWAY**
A REVIEW OF THE
LIVERPOOL CARE
PATHWAY

More Care, Less Pathway

“Unsurprisingly, this Review has **uncovered issues strongly echoing those raised in the Mid Staffordshire Public Inquiry**: notable among the many similar themes arising were a lack of openness and candour among clinical staff; a lack of compassion; a need for improved skills and competencies in caring for the dying; and a need to put the patient, their relatives and carers first, treating them with dignity and respect”.

What did you learn from Francis?

What have you changed already?

Is this aligned to EoL care?

How do you know what you did post Francis was an improvement?

More Care, Less Pathway

“Many of the problems in the care of the dying highlighted in this report are due to **poor understanding among clinicians of existing guidance** in care for the dying, and an **unwillingness to discuss** with patients, their relatives and carers the prospect of death and the clinical uncertainties that accompany it”.

NACD also suggests staff don't discuss key issues reliably with the patient

Are your staff *talking with and listening to* their patients and making care plans? ACP? ?

Are you talking to and teaching your staff about EoL Care? Are staff using their learning reliably?

Are they breaking through or down personal and organisational barriers?

Are your clinical leaders acting as leaders?

More Care, Less Pathway

It's Urgent and Important

Recommendation 3

“The name ‘Liverpool Care Pathway’ should be abandoned, and within the area of end of life care, the term ‘pathway’ should be avoided. An ‘end of life care plan’ should be sufficient for both professionals and lay people”.

LACDP

“Use of the ‘Liverpool care Pathway’ will be phased out by 14 July 2014. Whenever someone is in the last few days and hours of life, care must be focused around achieving the five Priorities for care, one of which explicitly requires an individual plan of care and treatment for those in the last few days and hours of life to be delivered”.

but improvement takes time

ONE CHANCE TO GET IT RIGHT

Improving people's experience of care
in the last few days and hours of life.

Published June 2014 by the
Leadership Alliance for the Care of Dying People

Publications Gateway Reference 01509

One chance to get it right

- is **compassionate**
- is based on and **tailored** to the needs, wishes and preferences of the dying person and, as appropriate, their family and those identified as important to them
- includes **regular and effective communication** between the dying person and their family and health and care staff and between health and care staff themselves
- involves **assessment** of the person's condition whenever that condition changes and **timely and appropriate responses** to those changes
- is **led** by a senior responsible doctor and a lead responsible nurse, who can access support from specialist palliative care services when needed
- is **delivered** by doctors, nurses, carers and others who have **high professional standards** and the skills, knowledge and experience needed to care for dying people and their families properly.

nothing less will do.

Priorities for Care of the Dying Person

Duties and Responsibilities of Health and Care Staff

Published June 2014 by the
Leadership Alliance for the Care of Dying People

Local palliative care contact:

RECOGNISE

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 and decisions revised accordingly.

Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc.

COMMUNICATE

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

INVOLVE

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.

SUPPORT

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

PLAN & DO

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

If unsure, or the dying person or those important to them raise concerns, a senior clinician must review the person and the goals and plan of care. The titles above are intended as memory prompts and attention should be paid to the whole description for each section. Expanded explanations are included overleaf.

Expanded explanations of the priorities

Recognise

- Consider potentially reversible cause if person unexpectedly deteriorates. A doctor must assess if change is potentially reversible or if person is likely to die within a few hours or days.
- If potentially reversible, take prompt action to attempt this, provided in accordance with person's wishes (or best interests, if lack mental capacity).
- If likely to die very soon, communicate this clearly and sensitively to the person (if conscious and have not indicated they would not wish to know) and family and those important to the person.
- Take into account the person's views and preferences, and develop and document plan of care.
- Regularly review person to make sure plan of care remains appropriate and respond to change in condition, needs and preferences.

Communicate

- Remember that open, honest and sensitive communication is critically important.
- Use clear, understandable and plain language – verbally and in all other forms of communication.
- If needed, provide additional support to help dying person understand information, communicate their wishes or make decisions.
- Remember that communication is two-way. Listen to views of person and those important to them, not simply provide information.
- Be sensitive, respectful in pace and tone of communication, and take account of what the dying person and those important to them want, and feel able, to discuss at any particular point in time.
- Check the other person's understanding of information that is being communicated, and document this.

Involve

- Involve the dying person to the extent they wish to be:
 - in day to day decisions about food, drink and personal care
 - in clinical and treatment decisions.
- Find out, and respect, the extent to which individuals wish their families and those important to them to be involved in decision-making.
- Tell the person, and those important to them, who is the senior doctor who has responsibility for their treatment and care, and who is the nurse leading their care.
- Where it is established that the dying person lacks capacity to make a particular decision, that decision or action taken on their behalf must be in their best interests. Involve them as far as possible.

Support

- Remember that families and those important to the dying person, including carers, have their own needs which can be overlooked at this time.
- Recognise that they may be physically and emotionally tired, anxious or fearful.
- Ask about their needs for support or information, and meet these as far as possible.
- Listen to, and acknowledge their needs and wishes, even when it is not possible to meet all of them.
- Where a dying person lacks capacity, explain the decision-making process to those people who are supporting the dying person and involve them as much as possible.

Plan & Do

- Develop an individualised plan of care and treatment to meet the dying person's own needs and wishes, and document this so that consistent information is shared with those involved in the person's care and is available when needed.
- Pay attention to symptom control, including relief of pain and other discomforts.
- Pay attention to the person's physical, emotional, psychological, social, spiritual, cultural and religious needs.
- Support the person to eat and drink as long as they wish to do so.
- Refer to specialist palliative care if the person and/or situation require this, and ring for advice if unsure about anything.

Each individual must have an individual care plan according to their needs. The plan should be discussed openly with the person and those identified as important to them. This plan must be reviewed on a daily basis.



Scan on a smartphone for quick access to website guidance

For further guidance www.nhs.uk/endoflifecare



**National care of the dying
audit for hospitals, England**
Executive summary
May 2014

How well did your local Trust do?

The National Care of the Dying Audit for Hospitals, England

- new audit sampled people in hospital, regardless of whether they were supported by the LCP or other care pathways
- the questions changed to reflect the recommendations of the LCP Review
- 131 Trusts (90%), 6580 people who died in 149 hospitals in England between 1 May and 31 May 2013
- questionnaires completed by 858 bereaved relatives or friends, asking about the treatment of their relative, their involvement in decision making, and the support available to them.
- availability of palliative care services, numbers of staff, training, and responsibilities for care.

Results found significant variations providing data for hospitals to identify good and poor practice, and **enable them to make changes** that will enhance learning and improve care for dying patients. They also **provide commissioners with an evidence base to make commissioning decisions.**

Organisational element key findings

- **Only 21% of sites had access to face-to-face palliative care services 7 days per week**, despite a longstanding national recommendation that this be provided; most (73%) provided face-to-face services on weekdays only.
- **Mandatory training** in care of the dying was **only required for doctors in 19% of trusts and for nurses in 28%**, despite national recommendations that this be provided. 82% of trusts had provided some form of training in care of the dying in the previous year; 18% had not provided any.
- **53%** of trusts had a **named board member** with responsibility for care of the dying. In 42% of trusts care of the dying had not been discussed formally at trust board in the previous year and only 56% of trusts had conducted a formal audit of such care, despite previous recommendations that this be carried out at least annually.
- **Only 47%** of trusts reported having a formal structured process in place to capture the **views of bereaved relatives or friends** prior to this audit.

Case Note Review key findings

Most patients (87%) had documented recognition that they were in the last hours or days of life, ***but discussion with patients was only documented in 46% of those thought capable*** of participating in such discussions. Communication with families and friends was recorded in 93% of cases.

Documentation of discussions about spiritual needs in only 21% of patients thought capable of participating.

In only 25% of cases was it documented that relatives/carers were asked about their own needs.

Most patients (63-81%) had medication prescribed 'as required' for the 5 key symptoms which may develop at the end of life. In the last 24 hours of life, 44% received medication for pain and 17% for dyspnoea. 28% had a continuous subcutaneous infusion of medication via a syringe driver.

Case note review element key findings

An **assessment of the need for clinically assisted (artificial) hydration** was recorded for **59%** of patients, but discussions with the patient were recorded ***in only 17% of those thought capable***. There was documented discussion with relatives and friends in **36%** of cases. CAH was in place in **29%** of patients at the time of their death.

An **assessment of the need for clinically assisted (artificial) nutrition** was recorded for **45% of patients**, but discussions with the patient recorded in ***only 17% of those thought capable***. There was documented discussion with relatives and friends in **29%** of cases. CAN was in place in 7% of patients at the time of their death.

In keeping with national guidance, most patients (82%) were assessed five or more times in the final 24 hours of life.

Look at the Cochrane reviews.

Local survey of bereaved relatives' views

key findings

- **76% reported being very or fairly involved** in decisions about care and treatment of their family member; **24% did not feel** they were involved in decisions at all.
- **Only 39%** reported being involved in discussions about whether or not there was a **need for CAH** in the last 2 days of the patient's life. For those for whom the question was applicable, **55% would have found such a discussion helpful.**
- **63% reported that the overall level of emotional support** given to them by the healthcare team was **good or excellent.** **37%** thought it only **fair or poor.**

Overall, 76% felt adequately supported during the patient's last 2 days of life; 24% did not.

Based on their experience, **68% were either likely or extremely likely to recommend their trust to family and friends.** 8% were extremely unlikely to do so.

Key recommendations 1

- Hospitals should provide a face-to-face **specialist palliative care service** from at least **9am to 5pm, 7 days per week**
- **Education and training** in care of the dying should be **mandatory** for all staff caring for dying patients.
- **Local audit of care** of the dying, including the assessment of the views of bereaved relatives, **at least annually**.
- **Designated board member and a lay member**, boards **formally receive and discuss the report of local audit** at least annually.
- The **decision that the patient is in the last hours or days of life** should be made by the **MDT and documented by the senior doctor responsible** (**discussed** with the **patient** where possible and appropriate, **and with family...**

Key recommendations 2

- Pain control and other symptoms in dying patients should be assessed at least 4- hourly and medication given promptly if necessary. **Interventions should be discussed with the patient where possible and appropriate, and with family etc**
- **CANH decisions are complex and should be taken by a senior experienced clinician supported by MDT, discussed with the patient where possible and appropriate, and with family...**
- Hospitals should have an **adequately staffed and accessible pastoral care team** to ensure that the spiritual needs of dying patients and those close to them are met.

The Leadership Challenge

“PfC expresses the common principles of good palliative care. The duties and responsibilities of health and care staff are to deliver them”

One Chance..p13 para 14

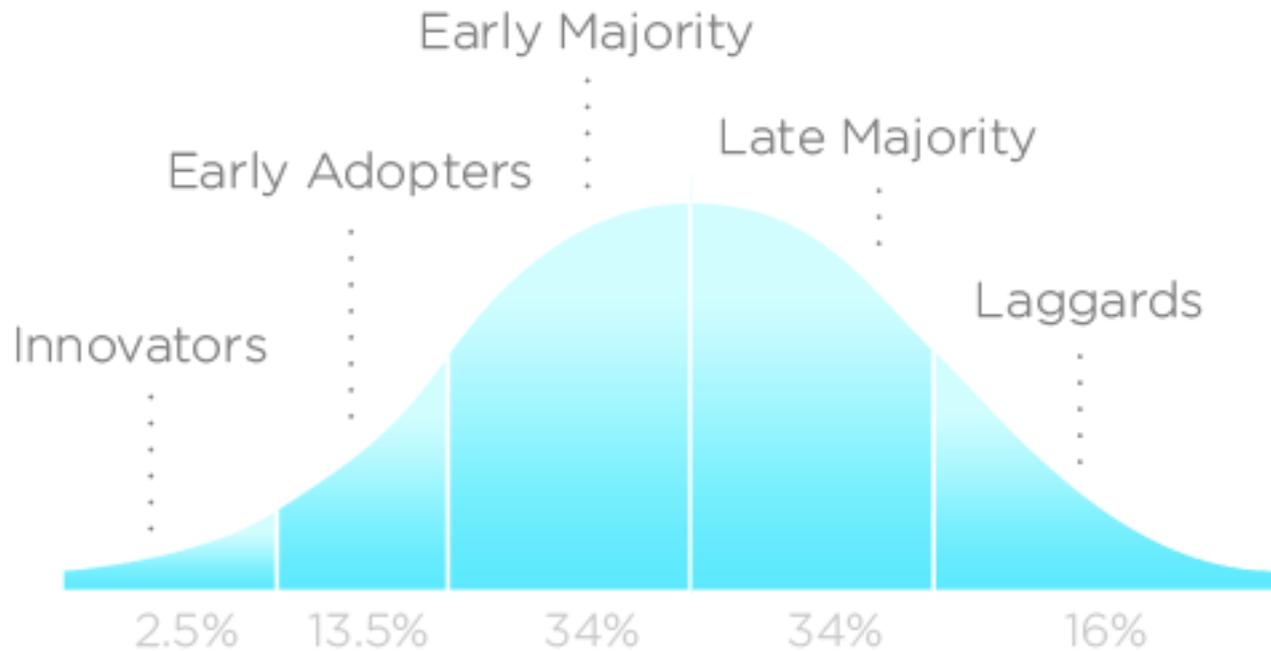
- The Moral Test (Berwick 2011)

- Effective leadership and great teams
- When great teams are not enough?
- Teaming up (HBR 2012)

- Create a sense of urgency (Kotter 2012)

- Unleash Positive Energy
 - Mobilize (and escape the traps)
 - Rebuild (remove the corrosive)
 - Focus, keep to the plan and improvement process
 - Sustain

Where are you now? Where do you want to be?



INNOVATION ADOPTION LIFECYCLE

Implementing the new Priorities for Care

One Chance to Get it Right (Pages 38- 40)

- Inspection and Regulation
- Commissioning
 - Stop inappropriate financial incentives
 - NHS Commissioning Assembly Task and Finish Group
- Organisational leadership and governance
- NHS England Mandate (positive experience of care domain and annual survey of the bereaved)

Urgent and Important. Don't panic, get a plan!



.....The watchdog has woken up

CQC- Inspection and Regulation

Safe - Effective - Caring - Responsive to Needs - Well Led

- New Inspection System
- Specific focus 2014-15
- Acute and Community, looking across all services
- Adult Social Care and Primary / GP services
- Vulnerable Older Peoples Plan
- Referral system back to NHS TDA, Monitor for action

Must do: Review published reports (CQC website)

CQC - End of life Care

Information about the service and a summary

- **Safe**
 - Incidents (being open; never events, serious incidents)
 - Medicines (prescribing, safety of opiates / syringe drivers)
 - Records
 - Consent, MCA, DoLs
 - (EoL Decisions: ACP, AD,DNAR, Best Interests. Vulnerable and Older People)
- **Effective**
 - Evidence based care and treatment
 - Pain relief, Nutrition and Hydration
 - Patient Outcomes
 - MDT working
 - Seven day services

CQC - End of life Care

- **Caring**
 - Compassionate care
 - Patient understanding and involvement
 - Emotional / spiritual / chaplaincy support
- **Responsive**
 - Services plans meet the needs of local people
 - Access (SPC) and flow (best place / fast tracking)
 - Meeting individuals needs
 - Facilities
 - Learning from complaints and concerns

CQC End of life Care

- **Well led?**
 - Vision and strategy for services
 - Governance, risk management and quality measurements
 - Leadership of services
 - Culture
 - Public and Staff engagement
 - Innovation, Improvement and sustainability

Being a Critical Friend

- Process
 - What we are doing?
 - What goes through my mind when I visit?
- Learning so far
- Top Tips

Strategy

- Do you have a local EoL Care Strategy?
- What was the strategy before LACD and how does it need to change?
- Is it based on your local values and aspirations of your staff and community?
 - Shared purpose? Owned by the many?
 - Harness the emotional intelligence, the passion and commitment?
 - Does it draw upon the wider strengths of the community of interest?
 - Is it aligned to local and relevant external relationships (CCG, HEE, other NHS providers, regulators)
- Is your strategy truly informed and realistic?
- Is it aligned to your Trust's over-arching Quality Strategy?
- Is the Board aware of potential risks to the quality of end of life care?

Capabilities and Culture

- Does the Board have the necessary leadership, skills and knowledge to ensure the delivery of the EoL care and broader quality agenda?
- Is your council of governors involved?
- Do your lead clinicians and managers have leadership and QI capability?
- Do the leaders in the Trust promote a quality focused culture?
- Frontline - ready and resourced or exhausted and demoralised??

Processes and Structures

- Are there clear roles and responsibilities in relation to quality governance and EoL care?
- Is it on the agenda? Is it at the right committees / forums?
- Is EoL Care (clinical outcomes) on the quality dashboard?
- Are there clearly well defined, well understood processes for escalating and resolving risk and managing the quality of EoL care?
- Does the Board actively engage patients, staff and other key stakeholders on the quality of EoL Care?

Measurement

- Is appropriate quality information being analysed and challenged?
- Is the focus on patient and family centred outcomes (avoiding unnecessary process measures where possible)?
- Is the Board assured of the robustness of the quality information?
 - Quality Improvement method
 - Clinical Audit / Internal Audit plan
 - Peer review, independent audit and assurance
- Is quality information used effectively?
 - Is it driving and delivering improvement?
 - Does it reduce / control risk?

Critical Friend: Interim Findings

- Board
 - Competing interests? Reactive not Proactive? Risk not seen / not seen in context?
- CQC
- SPC
- Engagement and Support
 - Executive team; Consultants; GPs; Nursing
- Under representation of patients / families other key 3rd parties
- Networking and collaboration
- Leadership, QG and QI Capabilities - measurement
- Clinical Governance systems
 - Clinical audit; education; Risk management; M+M; Incidents ; complaints etc
- Implementation: a couple of good examples but
 - Length; content and presentation; fit with other systems; supporting information; education; testing (EBCD) and improvement; transparency and accountability
 - Information giving, sharing, recording (the care plan guides then captures the discussions)
 - Unrealistic estimates of change, its trajectory and improvement schedules
 - Naivety about systems and constraints

Top Improvement Tips

1. Find and work closely with an executive sponsor
2. Be clear what your trying to improve
3. Get your change story really sorted so it makes sense every time you tell it: case for change, challenge ahead, benefits it will give
4. Build a collaborative, use your networks
5. Know where you are starting from
 - Maximise the information you currently have
 - Work out what information you need to get
 - Baseline key prospective outcomes, ensure measurement is reliable
 - Triangulate, analyse, predict, target
 - Cycle through improvements

Top Improvement Tips

6. Be clear and disciplined about the improvement process and manage expectations
 - project improvement aims and plans
 - timescales, key milestones, sequence, constraints, comms plan
 - responsibilities and accountabilities, get in on and up *“the agenda”*
 - make change accessible and involve the wider team (simple PDSA)
 - use similar concepts of previous successful change programs
 - be transparent to all, experienced based co-design helps
 - understand, talk about and manage risks
 - don't underestimate the educational support to change and maintain performance
 - acknowledge, reward, grow talent

Lastly, don't be afraid of

- Challenging a system where there is so much to gain and much more to lose
- Asking for things that you think you might not get.....my patients want free car parking, we need more staff because...
- Telling your change story, the good as well as the things that need improving
- Speaking up, out and together
- Listening to achieve a deep understanding of peoples ideas, concerns and expectation before they grow into fears
- Accepting the leadership / team challenge

Never Give Up!

Be relentless in your pursuit of excellence

10 Rules for Care Delivery Redesign

1. Care is based on a continuous healing relationship
2. Care is customised to patients needs and values
3. Knowledge is shared and information flows freely
4. Patient is the source of control
5. Decision making is evidenced based
6. Safety is a system property
7. Transparency is necessary
8. Needs are anticipated
9. Waste is continually reduced
10. Cooperation among clinicians is a priority

Institute of Medicine 2001

How to Improve

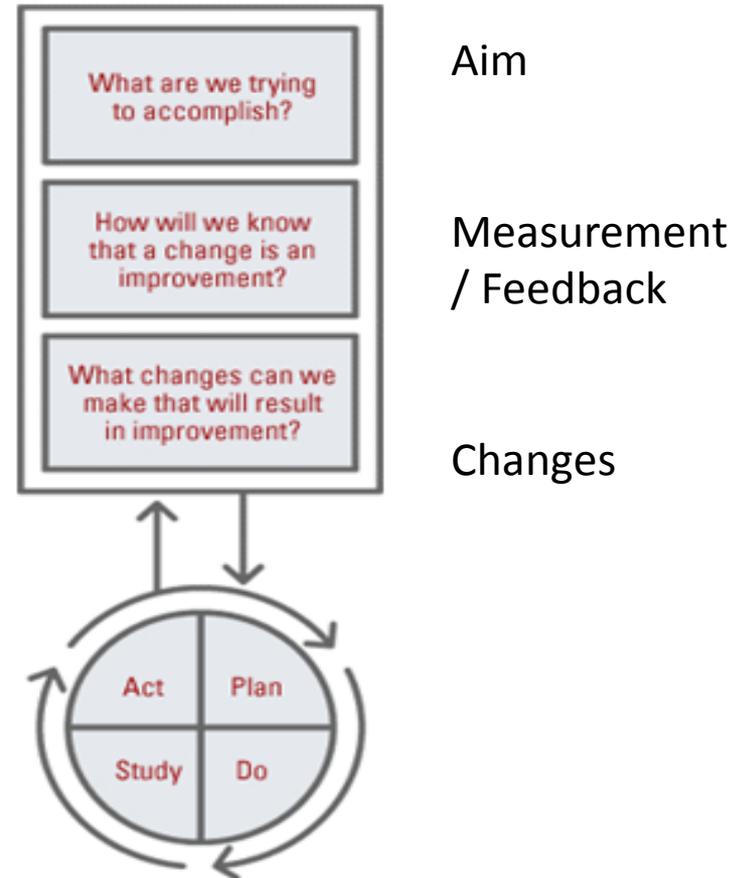
IHI uses the Model for Improvement as the framework to guide improvement work. The Model for Improvement,* developed by [Associates in Process Improvement](#), is a simple, yet powerful tool for accelerating improvement. This model is not meant to replace change models that organizations may already be using, but rather to accelerate improvement.

Learn about the fundamentals of the Model for Improvement and testing changes on a small scale using Plan-Do-Study-Act (PDSA) cycles.

- [Introduction](#)
- [Forming the Team](#)
- [Setting Aims](#)
- [Establishing Measures](#)
- [Selecting Changes](#)
- [Testing Changes](#)
- [Implementing Changes](#)
- [Spreading Changes](#)

*Source:

Langley GL, Moen R, Nolan KM, Nolan TW, Norman CL, Provost LP. [The Improvement Guide: A Practical Approach to Enhancing Organizational Performance](#) (2nd edition). San Francisco: Jossey-Bass Publishers; 2009.



IHI Core Strategies for Driving Improvement

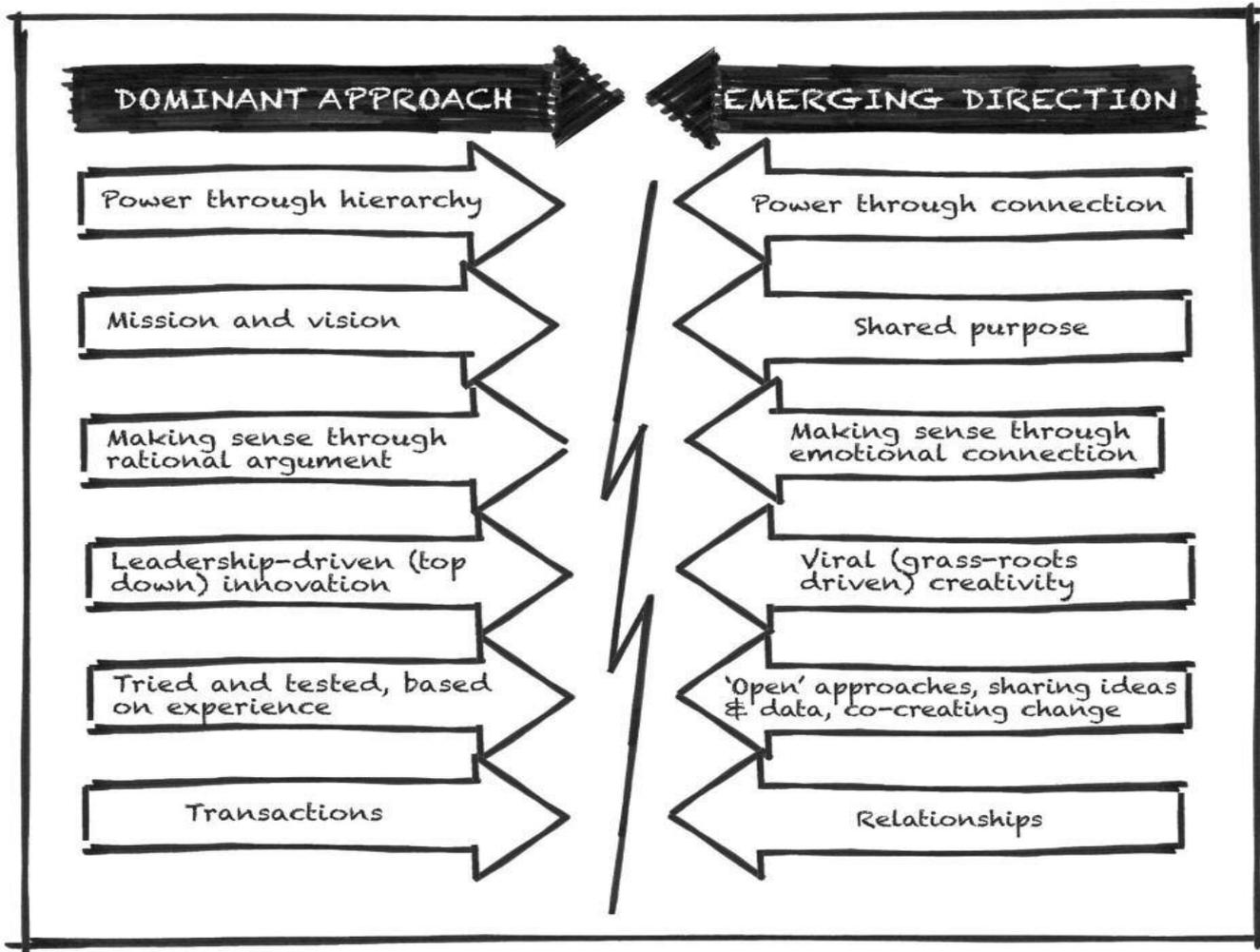
- **Motivate** (stimulate the desire for change)
- **Innovate** (create / find and test new ideas)
- **Get results** (spread what works reliably)
- **Raise joy** (and build capability)
- **Stay Vital**

6 Leadership Actions

- **Know your organisation's current performance**
- **Set bold and measureable aims**
- **Prepare people for success**
- **Establish systems to support effective care delivery**
- **Create measures and accountability**
- **Remove external barriers, align incentives**

Kabcenell and Conway 2011

Leadership: influencing styles and factors



The new era of thinking and practice in change and transformation NHS IQ July 2014

Before the Group work

Think

About your role and what you can contribute

Feel

Allow yourself to feel what success and failure might be like

Decide how truly these feelings motivate you

Act

With a shared purpose

Communicate

Be a good listener