NHS
Improving Quality

LESSONS LEARNED

Implementing an Electronic Palliative Care
Co-ordination System (EPaCCS)

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THE WHAT!

Electronic Palliative Care Coordination Systems (EPaCCS) provide a means of recording and communicating key information about people's wishes and preferences for end of life care. The ultimate aim is to improve coordination of care so that End of Life Care wishes can be met at the point of care, and more people are able to die in the place of their choosing and with their preferred care package.

The End of life Care Strategy (2008) identified the need to improve the co-ordination of care, recognising that people at the end of life frequently received care from a wide variety of teams and organisations. The developments of Locality Registers (now Electronic Palliative Care Co-ordination Systems known as EPaCCS) were identified as a mechanism for enabling co-ordination.

THE WHY?

Information from 2013 Voices survey on coordination of care:
- Quality of care was rated significantly lower for people who died in a hospital, compared to people dying at home, in a hospice or care home
- For those dying at home, the quality of coordination of care was rated significantly lower in 2013 compared to 2012.[1]

"When the sharing of up-to-date information about a patient and their wishes across agencies works effectively, it is the most brilliant thing and makes a huge difference to the patient, family and those involved with the patient. We all need to hold on to that thought when working through the implementation difficulties!"

Wandsworth CCG

"One GP working here on Saturday had two palliative care home visits where he was able to locate the information required within S1 on EPaCCS. It assisted him to make much more appropriate, quick clinical decisions using the correct specialist, whose information was within the patient record."

Out of Hours Manager, LEEDS

[1] National Survey of Bereaved People (VOICES), 2013 -http://www.ons.gov.uk/ons/dcp171778_370472.pdf

THE HOW!

DO

Do…

Ensure you have agreed your local vision and have gained commitment from all stakeholders.

Organisations deemed as 'successful' are those whose communities are strong, passionate and committed to delivering improvement and outcomes and who create shared purpose as a common thread.

Local teams need to identify all stakeholders and ensure that there is a shared understanding of the vision and task.

Do…

Work together across localities

Implementers who are progressing well are those working in partnership e.g. "Co-ordinate my Care" and the North West EPaCCs Implementation Group.

The 2013 implementation survey identified 34 different partnerships involving 136 CCGs = 65%.

Partnerships between CCGs involved many different agencies working together i.e. Ambulance Trusts, hospices, providers and out of hours service.

Many are working with support from their Clinical Support Units and SCN in developing a local solution.

Source: Electronic Palliative Care Co-ordination Systems (EPaCCS) in England: Survey of clinical commissioning groups (2013) www.endoflifecare intelligence.org.uk/resources/publications/epaccs_in_england

DON'T

Don't…

Underestimate the time and effort required in setting up and getting started.

Many teams report this as 'the hardest part', having a large project group can often hinder decision making. Identify a small number of key individuals, both at a senior and operational level, who it would be worthwhile sounding out.

If you are unsure who these individuals are, you can use stakeholder analysis to help you identify them.
- Stay focussed and take small steps
- Teams report having support from the national team can act as a catalyst to getting started

Don't…

Try to solve the issues alone

Progress is reported slower in teams working in isolation.

51 CCGs = 25% reported working alone. Only 11 stated they had fully operational systems, 28 stated planning had started, 9 no planning at all and 3 status unknown.

Source: Getting started including information on the Information Standard www.endoflifecare-intelligence.org.uk/view?rid=742

DO

Do…
Ensure you have clinical engagement /leadership

Identify champions at senior level. Use them to explain the benefits of EPaCCs to other clinicians.

Having a designated board member with specific responsibility for end of life care ensures it has the right level of attention both in and across organisations.

Do…
Recognise that the IT landscape is complex however, there are solutions

CCGs reported different lead technical systems were being used for EPaCCs. In a quarter of CCGs with systems planned (27 CCGs, 24%), it was indicated that multiple systems would be used.

Although many operational EPaCCS are in their infancy, some CCGs reported that they were able to share information through EPaCCS with clinical systems.

Align yourself as far as possible with existing IT clinical systems and strategies. Remember to consider issues such as data sharing models in your locality and initiatives such as mobile working.

DON'T

Don't…
Underestimate staffs resistance to change and working differently

Communicate progress and celebrate successes. Don't waste energy on trying to persuade resisters. Concentrate on those with enthusiasm for change.

Don't…
Get stuck on issues around information governance and interoperability

- Learn from others who have made progress in spite of issues
- You don't have to solve it all at once!
- You need an approach that allows for small incremental steps
- This can support a local 'roadmap' towards fully interoperable solutions

Source: Resources available to support implementation, the Interoperability Toolkit
www.endoflifecare-intelligence.org.uk/view?rid=742

http://systems.hscic.gov.uk/qipp/library/carecoordtk-fs.pdf

http://systems.hscic.gov.uk/qipp/library

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DO

Do…
Provide education/training for all users

In order to get a high quality patient centred care plan on an EPaCCs, workforce planning and training was essential.

Training should include;
- How to use the system
- Consent process and capacity assessment
- Identification of patients in the last year of life
- Identification of carer
- Communication skills to enable conversations on future care.

Difficult conversation training is key to improving communication and usage of EPaCCs.

Do…
Remember language is important!

It is important for patients and relatives to understand and have confidence that it is a supportive system to coordinate their care and provide further information to support implementation.

Source:
www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/coordination-of-care.aspx

Do…
Keep connected – remember to share learning

Access information, seek knowledge. You do not know what you do not know! Teams value access to local networks and practical workshops.

DON'T

Don't…
Rely on a cascade model

Teams report the importance of engaging with and training individual users.

Every GP in each practice.

Engage with community nursing at an early stage.

Do not assume they all have the skills and knowledge in IT.

Don't…
Just develop another register or say 'the patient is placed on an EPaCCs'

Individuals will feel as though they are being processed rather than considered as an individual. Saying "An individual person is supported by a system to coordinate their care" puts the focus on the benefit to the individual and those who are important to them. It has a sense of a person being recognised as an individual and having more control over what they can control.
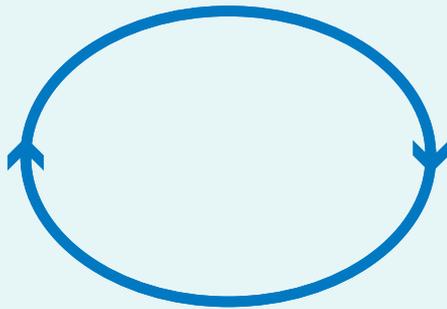
Don't…
Struggle, help is available

Talk to teams implementing EPaCCs and learn from their mistakes and how they overcome issues and challenges.

Different thinking for different results

Transitional change

Designing a coordinated system

- **A focus on methods, systems and behaviours**
- **Improving what we know already (structures, systems, implementing best practices)**
- **New payment systems**
- **Refining incentives**
- **Measures of success**
- **Make the current system 'leaner' and less wasteful**
- **Performance improvement**

**Transformational change**
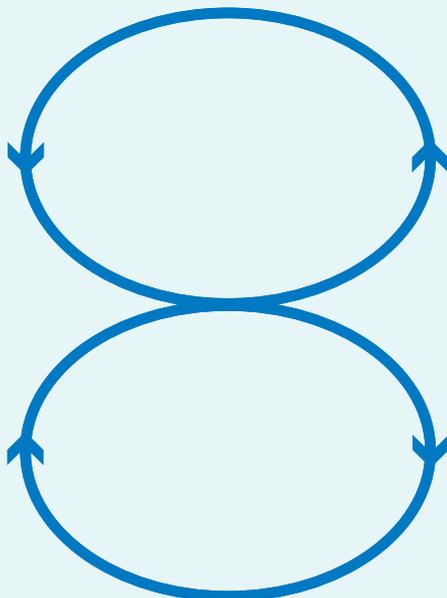
Building an enduring capacity for change

- **Changing the way we think about the problem**
- **Not just changing behaviours but beliefs and assumptions**
- **Exploring unusual and innovative alternatives**
- **Requires a high tolerance for ambiguity and paradox**
- **Shifting power by designing a truly person-centred system**
- **Continuously learns, adapts and improves**

For further information on Leading Large Scale Change visit:
http://www.nhsiq.nhs.uk/8530.aspx
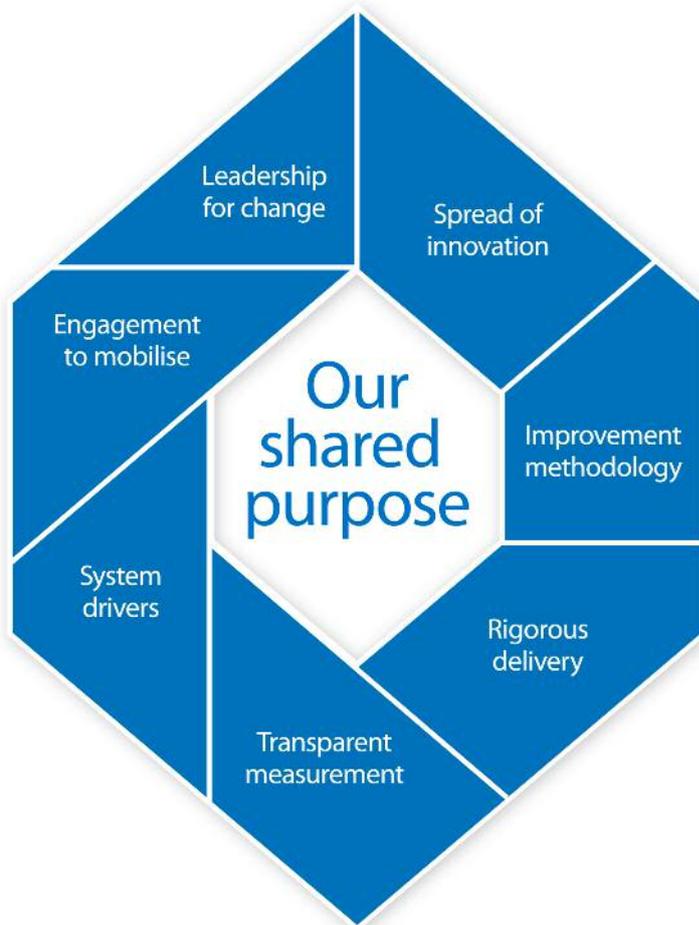
- **Connects people**
- **Helps us understand each other's roles in change, our strengths and preferences**
- **For everyone (including those outside the NHS)**
- **A framework rather than a model?**
- **Based on collective experience of delivering change**
- **Key ideas supporting the model:**
  - **Energy for change**
  - **Compliance and commitment**
  - **Extrinsic and intrinsic motivators**

www.changemodel.nhs.uk

For further information and resources visit: www.nhsiq.nhs.uk/endoflifecare

To find out more about NHS Improving Quality:

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