Critical Success Factors for the Improvement of End of Life Care in Primary, Community and Acute Services

Damian Hodgson, Simon Bailey, Mike Bresnen, Paula Hyde, and Rachel Ward

This research was commissioned by Pennine Care NHS Foundation Trust.

Evaluation Aim

> To me, End of Life Care is absolutely at the heart of our business. We don't think it is as doctors, but it is. My view is if you can't get this right you probably can't get anything else right.
>
> (Clinician, Acute Trust)

Mixed-methods study of End of Life Care conducted across three regions in the North of England between 2011-2012.

Drawing on quantitative and qualitative data, the study;

1. Examines Death in Usual Place of Residence (DiUPR) as a proxy for high-quality, choice-led end of life care.
2. Analyses the critical success factors which shaped the differing performance of the three boroughs in this study in relation to DiUPR.

Literature Review

PubMed Search Terms:

- (“End of life” OR “palliative”)
- AND (“preference” OR “death at home”)

- 600 manually searched titles and abstracts
- 43 of direct relevance

Policy and Reports

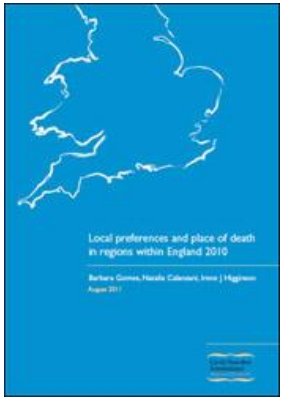
Preferred Place of Death

- For many patients, Preferred Place of Care differs from Preferred Place of Death (Gerrard et al, 2011)

- Hospital was the *least* preferred place of death in all but one of the English regions.
  - Excepting 16-24 year olds, only a small minority of each age group (1-5%) expressed a preference to die in hospital.

- A preference to die at home and in a hospice has increased in most regions over the last decade.

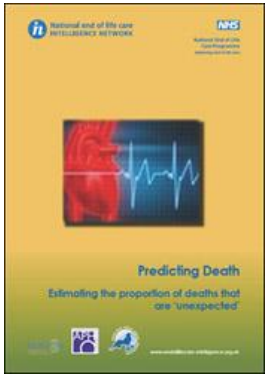
- Preference to die at home decreased as age increased; preference to die in a hospice increased as age increased. (Gomes et al, 2011)



Policy and Reports

Predictability of Hospital Deaths

- Study combining ONS mortality data and Ministry of Justice Coronial Service Statistics concludes;
- "At least 25% of all deaths in England and Wales are unexpected deaths from sudden causes"
    - (NEoLCIN/South West Public Health Observatory, Feb 2011)



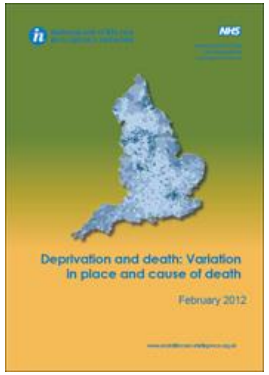
- "Only 20% to 33% of patients who died in hospital could have been looked after at home." (Abel et al, 2009*)*

- There are (in current conditions) absolute boundaries on facilitating deaths outside hospital settings.
- For some, hospital remains the best, or the only, option.

Policy and Reports

Correlation between Deprivation and Place of Death

- Death in hospital more common in the most deprived quintile.
  - People from the most deprived quintile are, on average, 29% more likely to die in hospital than the least deprived quintile
- Death in care or nursing homes less common among people living in the most deprived quintile (11%) than any other quintile (16–20%).
- A range of intervening factors were identified which vary by deprivation index e.g. incidence of smoking-related cancers, availability of care/nursing homes, etc.



- Source: *Deprivation and death: Variation in place and cause of death* (NEoLCIN/South West Public Health Observatory, Feb 2012)

Policy and Reports

Summary

- Most people would prefer to die outside of hospital – either in own home/usual place of residence (e.g. care home) or hospice.
    - Around 93% of people wish to die at home or in a hospice, but around 53% still die in hospital (Gomes et al, 2011)
- Deaths in Usual Place of Residence (DiUPR) is a reasonably accurate proxy of Preferred Place of Death in the majority of cases.

- Various challenges to coordination of care necessary to enable/support death in usual place of residence
    - **Situational**
    - **Organisational**
    - **Contextual**

Literature Review

- **Barriers to fulfilment of patient preferences:**

1. Situational factors:
   I. Preferences are 'inherently uncertain', change over time and are shaped by both HP and SU knowledge of services
   II. Age, gender, cause of death and especially socioeconomic status affect the likelihood of dying in or outside hospital

2. Organisational factors:
   I. GPs: variations in purpose & vision regarding EoL, process and protocol regarding communications between professionals.
   II. Acute hospitals: treating illness rather than person, preferences may reflect personal/social ethics rather than medical. Death at home unlikely to be presented as an option in acute settings

Literature Review

Barriers to fulfilment of patient preferences:

Contextual factors:

1. **Complexity of service area:**
    I. Large number of stakeholders: service users, carers and families, many different healthcare professionals
    II. Challenge of recognising importance of family support and engagement in context of the different expectations often held by SUs and their families
2. **Inter-professional issues:**
    I. GPs and acute, GPs and district nurses, specialist and district nurses. Difficult relations between care homes and other health services.
3. **Disease specific issues:**
    I. Research, policy and practice dominated by cancer
    II. Dementia presents most difficult issues regarding preferences and prevention of acute admission

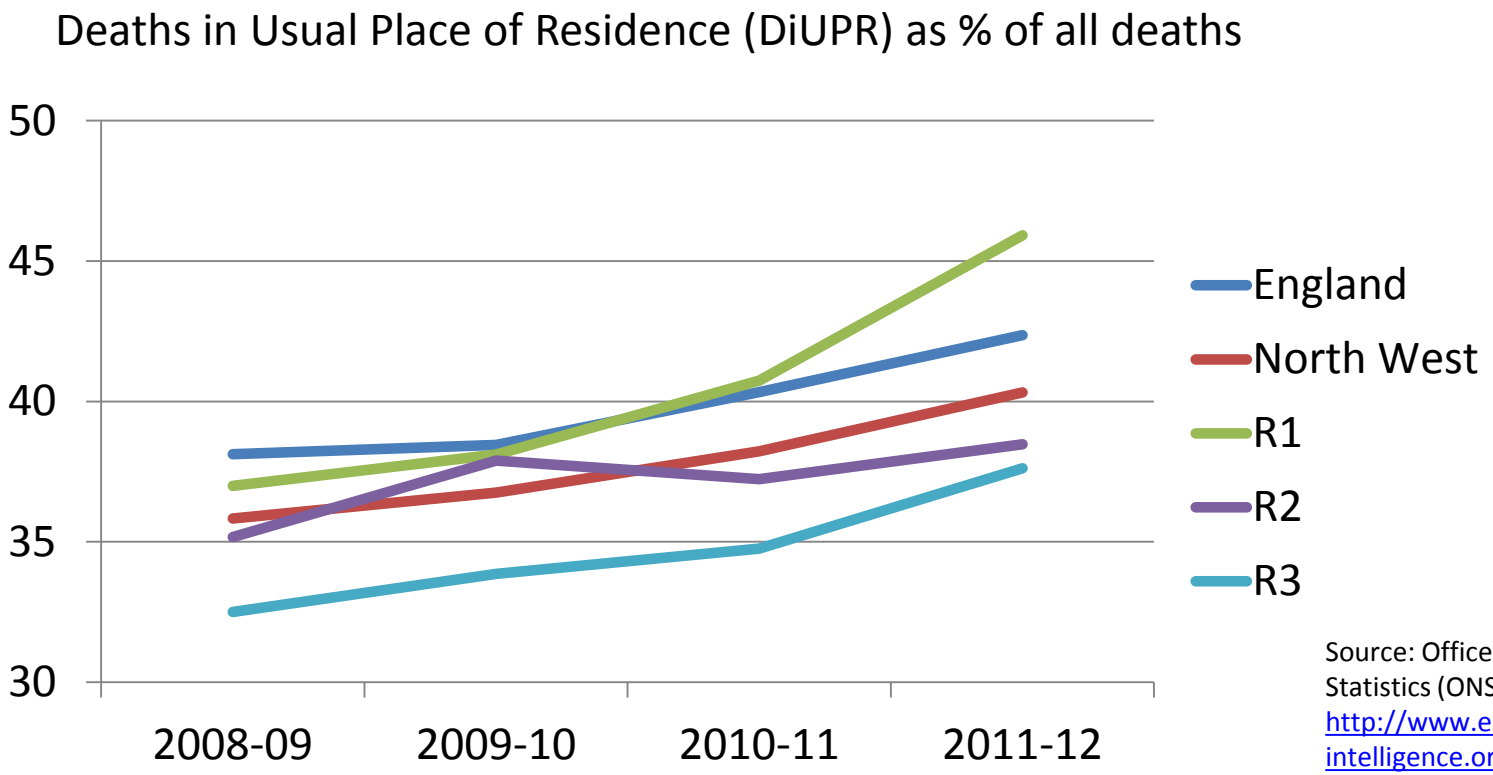
Evaluation Aim

- The overall aim of the evaluation was to identify critical success factors in relation to optimal EoL care in three areas in NW England (R1, R2 and R3)

- Focus in particular on the nature and causes of changes in performance in terms of place of death across R1, R2 and R3

- *Underlying questions;*
  1. *What has led to significant improvement in facilitating death outside of hospital in one of the three areas studied (R1)?*
  2. *Can this improvement be replicated, and if so how?*

DiUPR Regional/National Trends



Source: Office for National Statistics (ONS) http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death.aspx

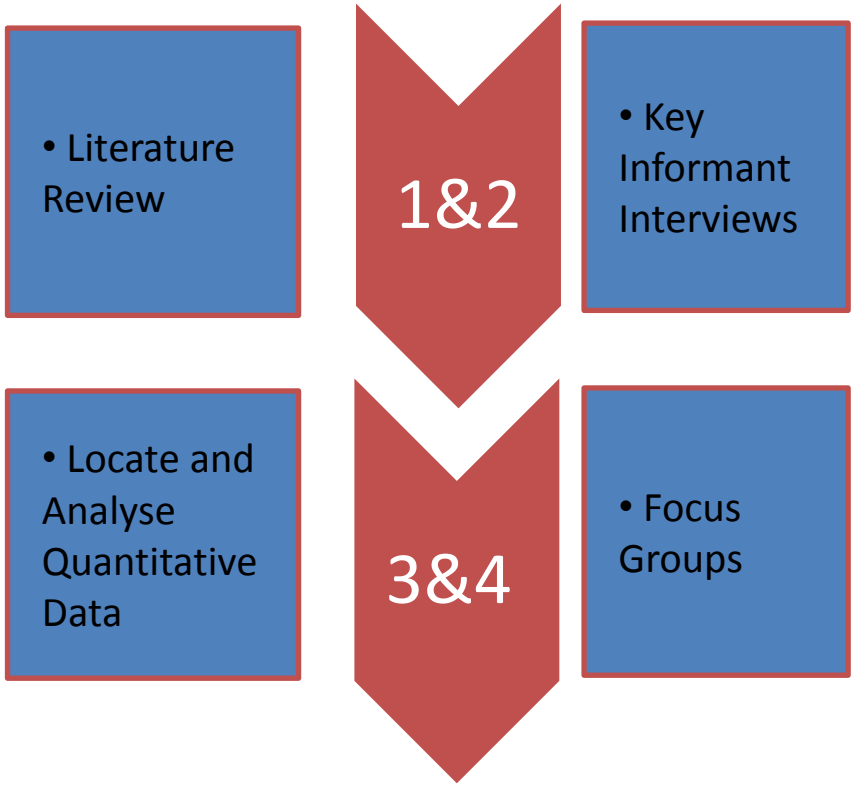
- Consistent 3-4 % point increase p.a. nationally and regionally
- R1 significantly exceeds this

Methodology

1. Literature Search
2. Key Informant Interviews
3. Quantitative Analysis
4. Focus Groups/Interviews

Interviews Conducted:

Care Trust	13
Acute Trust	6
General Practitioners	7
Care Homes	3
CCG/CSU	5
Total	**34**



Identifying Improvement in R1

- In 3 years, R1 reduced deaths in hospital from 56% to 47%
- Around 150 people in R1 died in their usual place of residence in 2011-12 who might have been expected to die in hospital in 2009-10
- Majority of the shift away from hospital was taken up by care homes
- Little variation in DiUPR between GP practices (unlike R2/R3).
- Link between deprivation and poorer DiUPR outcomes supported.
- Also link between ethnic/religious diversity and poorer DiUPR outcomes
  - several reasons suggested in qualitative research.

"DiUPR+" (including hospices)

	% Deaths in Hospital	% Deaths in Own Home	% Deaths in Care Home	% Deaths in Hospice	% DiUPR	% DiUPR+	Elsewhere
R1	56.0	19.4	18.6	4.4	38.0	42.4	1.6
R2	56.5	19.2	16.3	**6.1**	35.5	41.6	1.9
R3	59.7	18.4	13.9	**6.6**	32.3	38.9	1.4
ENGLAND	54.5	20.3	17.8	5.2	38.1	43.3	2.2

Source: **National End of Life Care Profiles for Local Authorities 2012**

- Using DiUPR underrepresents the performance in R3 and R2
- Including hospices in DiUPR ("DiUPR+") reduces the difference between R1 and R2/R3 (reflecting greater hospice provision in R3 and R2)
- Nonetheless, using either measure, R1 has improved faster than the other two boroughs between 2008-2012

Tracking Improvements in R1

	09-10	10-11	11-12	Δ
Home	21%	22%	23%	+2
Hospice	5%	5%	6%	+1
Hospital	57%	51%	48%	-9
Care Home	16%	21%	22%	+6
Other Communal	2%	1%	2%	0
TOTAL	100%	100%	100%	

	09-10	10-11	11-12	Δ
Home	349	383	377	+28
Hospice	76	92	90	+14
Hospital	953	905	779	-174
Care Home	276	365	357	+81
Other Communal	32	21	33	+1
TOTAL	1686	1766	1636	

- The main reduction in % hospital deaths occurred between 09-10 and 10-11
  - Much of this was taken up by care homes
  - % dying at home or in hospices have shown little change

Critical Success Factors

1. Engagement and Commitment of GPs to EoLC
2. Policy and Practice of Acute Trusts
3. Care Home Training and Accreditation
4. Continuing Healthcare Funding

5. Impact and Stability of End of Life Facilitator

Critical Success Factors

- Engagement and Commitment of GPs to EoLC
  - Variation described in terms of documentation, GSF compliance, DNAR and anticipatory prescribing
  - Particular challenges around out of hours provision
  - Challenge of EoLC in terms of knowledge of services, inter-personal skills, and inter-professional relations

"If I'm perfectly honest here, it's the GPs that are interested in end of life care. If you have a supportive GP you've more chance of spending the last days of your life where you want to be." (Focus Group R3)

"Until the CCGs - I hope they are getting this! - until the CCGs tackle these GPs who are unwilling to engage…" (Focus Group R2)

Critical Success Factors

- Policy and Practice of Acute Trust
  - EoLC challenges the orientation of many acute clinicians
  - Discharge policy has undergone significant change.
  - Evidence of Consultant Outreach impact
    - Targeted on care homes with greatest challenges

Some consultants will do a ward round and they'll ask where the person wants to be and try and get them home if necessary. Others won't… You don't have to have a long conversation, or not as long a conversation, if you don't make any proactive decisions.

(Consultant, Acute Trust)

We're asking the GPs to go and do some of (the consultant outreach) work. Again, doing care plans, proactively engaging with relatives and family members to see what would you want to happen if this situation occurred. So we're almost industrialising it a little bit.

(CCG, R1)

Critical Success Factors

- Care Home Training and Accreditation
  - Qualitative and some quantitative support for effectiveness of GSF and Six Step
    - Reliant on capacity of homes to undertake and sustain learning
    - Tendency to target 'low hanging fruit'

"We're doing GSF with GPs and I did GSF with care homes. With both care homes there was a massive reduction, an absolutely massive reduction in admissions to hospitals at end of life."

(Focus Group R1)

"One home just sent an application form in: a few lines scribbled on the back of paper. And to us that wasn't good enough because it's hard work to undertake this programme … What we say on the programme [is], 'if you invest your time with us we will support you all the way and invest our time with you'." (Focus Group R3)

Critical Success Factors

- Continuing Health Care Funding
  - Qualitative consensus that R1 had easier access procedure for CHC funding
  - Highlights difficulty caused by budgeting boundaries between health and social care

> Having the person in hospital comes under healthcare. So you're on a lose/lose situation here if you keep them in hospital - if you're getting them out of hospital you're getting them into a lower cost environment pretty much in every case (Clinician, Acute Trust)

> Basically R1 say that they will fund things, fund the CHC straight off and then find out whether or not it should be them or social care or whatever afterwards. (…) If you're trying to get somebody through a system rapidly you just won't do it, so you might as well not have that system in place in those areas.. (Clinician, Acute Trust)

Critical Success Factors

- Impact and stability of the EoL facilitator
  - R1 significantly more stability in this regard than R2 or R3
  - Relates to several other success factors (e.g. GP and care home engagement)
  - Stability over time linked to perceived cultural change

R3 haven't had a facilitator, only up to the last eight-nine months maybe. And R2 had a facilitator but then she left not long after. So they didn't have the GP meetings, and to me that is a massive difference and to me that's probably what has made the difference really.

(Focus Group, R1)

It's took about 12 months to get where they're actually listening to what we've got to say really. But you can't go in all guns blazing – I keep plugging away really.

(Focus Group, R3)

Conclusions

- **Place of death is only a proxy for quality of end of life care**, but relies on commitment and coordination of activities which might be expected to impact on all aspects of EoLC
- Measuring the quality of end of life care can be improved by **extending DiUPR to include deaths in hospices via a revised index (DiUPR+)**.
- The **EoL Facilitator role/team (and continuity in it) is critical** in promoting coordination of care across professional and other jurisdictional boundaries and needs to be actively supported and developed at a local level.
- **Championing of EoLC among GPs practices have an increasingly dominant bearing upon quality of end of life care**, and improvements thus rely upon effective incentivisation.
- Improvements in DiUPR can be achieved by promoting the **proper training and accreditation of care homes**. Greater improvements in the long term requires extending reach to improve EoLC in hard-to-reach care homes.
- **CHC funding needs to take a flexible approach to budgetary boundaries between health and social care** to effect smoother transitions for patients from acute settings to the home/care home environment.
- More research is needed at both local and national level into preferences within **different ethnic and religious communities** in order to gain a better understanding of diversity in preferences and also to clarify the **precise links with deprivation**.

Future Research

- Greater Manchester CLAHRC is running a series of projects relating to palliative and end of life care
- Aim to replicate study looking at DiUPR+ across all of Greater Manchester
- This will inform various CLAHRC projects and hopefully also the design of a qualitative project on success factors and deprivation/ethnicity.

For more information please contact

- Damian Hodgson (damian.Hodgson@mbs.ac.uk)
- Gunn Grande (Gunn.Grande@manchester.ac.uk)