

# Auditing preferred place of care – what are the benefits and limitations?

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# Outline

- Background and national context
- Dorset Network Specialist Palliative Care Group - Audit of Preferred Place of Care and Place of Death
- Discussion of audit findings
- Benefits, limitations and potential harms
- Recommendations

# Background

- End of Life Care Strategy (DoH 2008)
  - Patient choice
  - Excellence in end of life care across all settings
- Advance care planning
  - National Guidelines, Royal College of Physicians February 2009
- Preferred priorities for care has not been adopted widely in Dorset

# The national agenda (1)

- 2001 Labour manifesto –
  - “We will give patients more choice”
- 2003 Building on the best – choice, responsiveness and equity in the NHS
  - End of life care initiative
- 2004 NICE Guidance - Improving Supportive and Palliative Care
  - “people’s preferences on the location of care are followed, whenever possible”
- 2007 Cancer Reform Strategy
  - delivering care in the most appropriate setting
  - avoiding unnecessary admissions

# The national agenda (2)

- 2008 End of Life Care Strategy
  - “that people’s needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible”
  - “provision of 24/7 services will avoid unnecessary emergency admissions to hospital and will enable more people to live and die in the place of their choice”
- 2009 End of Life Care Quality Markers
  - “measures and processes are in place to ensure that a patient’s wishes have been identified and, where possible, that patients who wish to die at home are able to do so”

# Dorset Network Specialist Palliative Care Group Recommendations

- *“If someone expresses a preference this should be recorded;*
- *there should be a single agreed place for this to be done.*
- *Patients should be offered the opportunity to express preference when clinically appropriate and the NSPCG would suggest using the following 3 questions to prompt discussion:*
  - *In relation to health what has been happening to you?*
  - *What are your preferences and priorities for your future care?*
  - *Where would you like to be cared for in the future?*
- *This is an ongoing process so notes of discussions must be dated”*

Dorset Network Specialist Palliative Care Group 16/07/08

- Note: not all patients will want, or have capacity to, discuss their preferences about end of life care

# Dorset Network Specialist Palliative Care Group

## Audit of preferred place of care - aims

- To identify current practice in documentation of patients' preferences for place of care and place of death
- To explore to what extent these preferences are met

# Audit of preferred place of care

## Objectives

- To establish a baseline for current practice in the documentation of preferences for place of care
- To establish to what extent the actual place of death is concordant with patients' most recently stated preferred place of care
- To identify if improvement or change in practice is needed
- To set appropriate standards before a reaudit in 2009/10

# Audit of preferred place of care

## Criteria

- Patients' expressed preferences for place of care should be documented in a standard place in the healthcare record
- Documentation of patients' preferences should be dated
- There is NO standard to say that a specific proportion of patients should have a documented preference for place of care

# Audit of preferred place of care

## Methods

- Dorset-wide prospective audit (01/12/08 – 28/02/09)
- 3 specialist palliative care providers: Weldmar, Poole Palliative Care Service (based at Forest Holme), Macmillan Unit Christchurch
- Population: all patients dying under the care of the specialist palliative care services
- Proforma to assess documentation of preferences in healthcare record and details of date and place of death (no patient-identifiable data)
- Simple statistical analysis

# Audit of preferred place of care

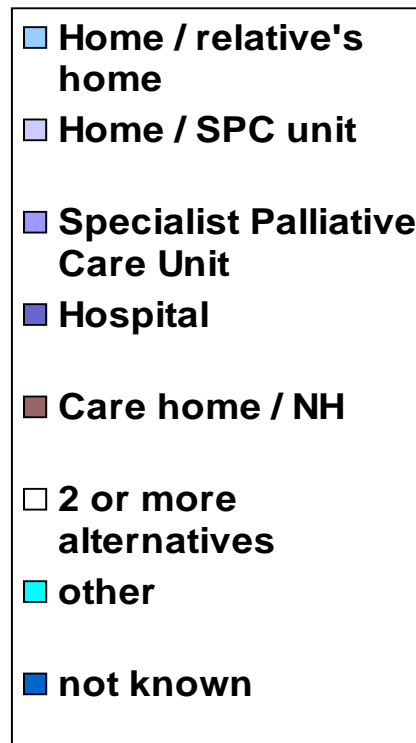
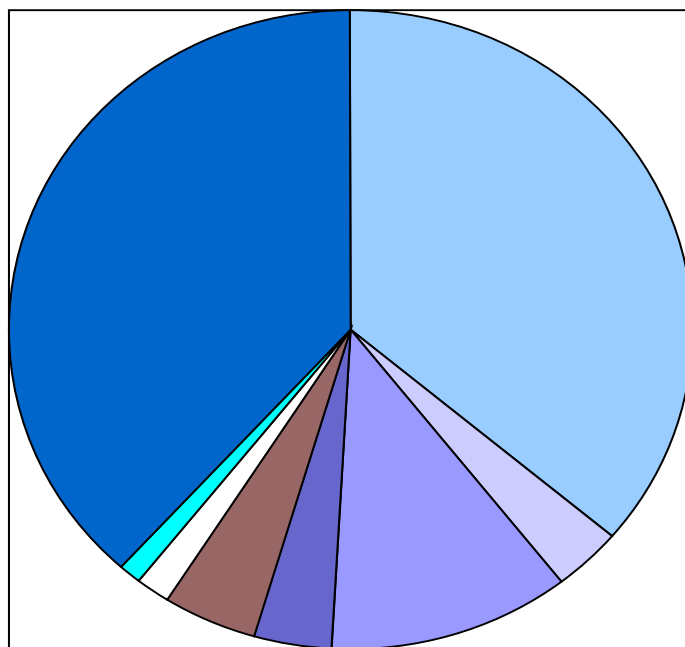
## Results

- Data collected for 470 patient deaths
- Documentation of preferred place of care:
  - 288 patients (61% of total deaths)
- Preferences documented in a standard place:
  - 233 (85%)
- Preferences dated:
  - 268 (98%)

# Most recently stated preference for place of care or place of death

|                                |     |     |
|--------------------------------|-----|-----|
| • Home / relative's home       | 170 | 36% |
| • SPC unit / hospice           | 53  | 11% |
| • Home or SPC unit             | 16  | 3%  |
| • Care home / NH               | 21  | 4%  |
| • Acute hospital               | 11  | 2%  |
| • Community hospital           | 6   | 1%  |
| • Home or comm. hospital       | 4   | 1%  |
| • Hospital or SPC unit         | 1   | <1% |
| • Home or SPC unit or hospital | 2   | <1% |
| • Not home                     | 1   | <1% |
| • Other                        | 5   | 1%  |
| • Unknown                      | 180 | 38% |

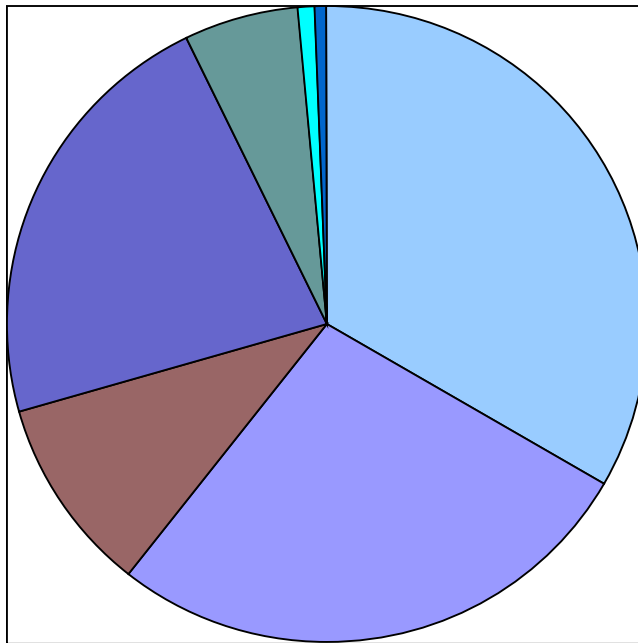
# Most recently stated preference for place of care or place of death



# Actual place of death

|                          |     |     |
|--------------------------|-----|-----|
| • Home / relative's home | 157 | 33% |
| • SPC unit               | 128 | 27% |
| • Acute hospital         | 105 | 22% |
| • Care home / NH         | 46  | 10% |
| • Community hospital     | 27  | 6%  |
| • Other                  | 4   | 1%  |
| • Not known              | 3   | 1%  |

# Actual place of death

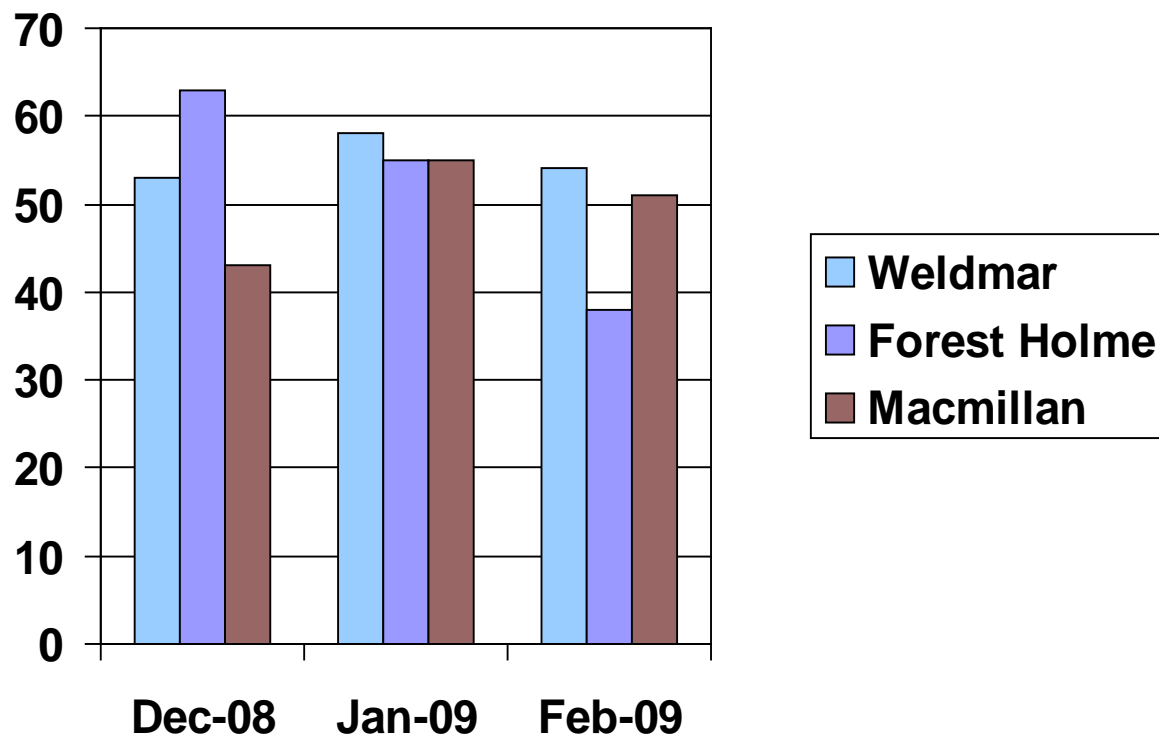


- Home / relative's home
- Specialist Palliative Care Unit
- Care home / NH
- Acute Hospital
- Community Hospital
- other
- not known

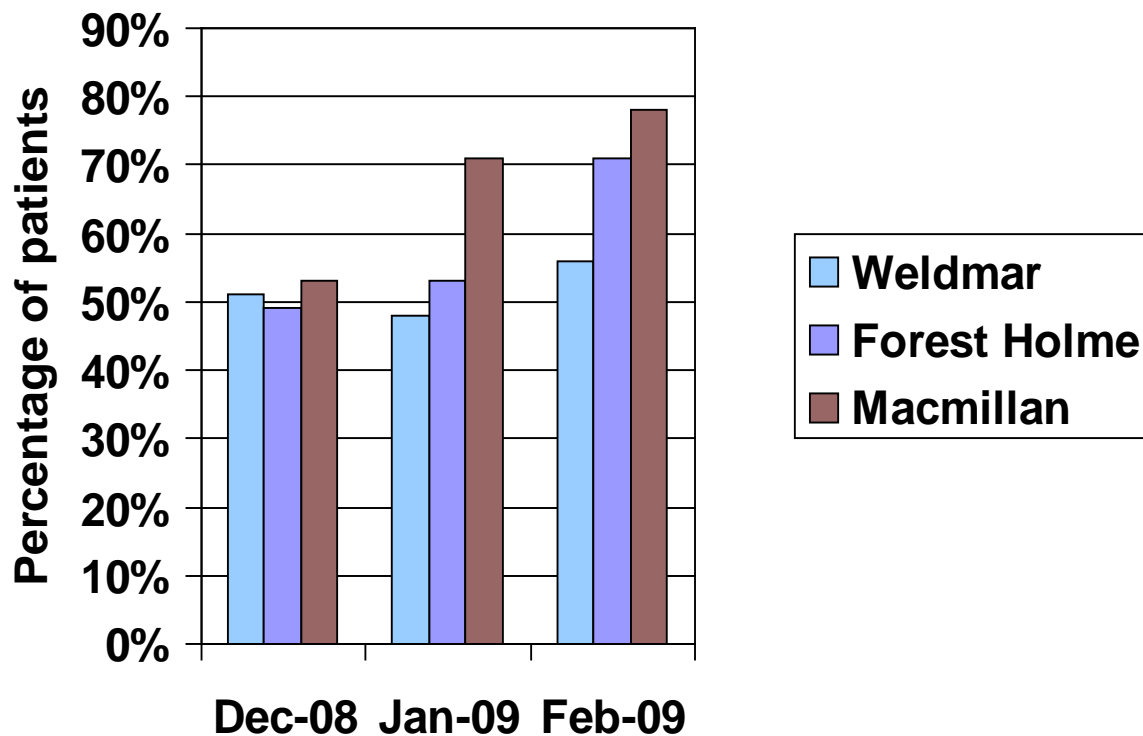
# Was the place of death in the most recently stated preferred place of care?

- For patients who had a documented preference, the place of death matched the most recently documented preferred place of care in 73%
- Note:
  - patients may change their minds;
  - some lack capacity to engage in discussion about place of care

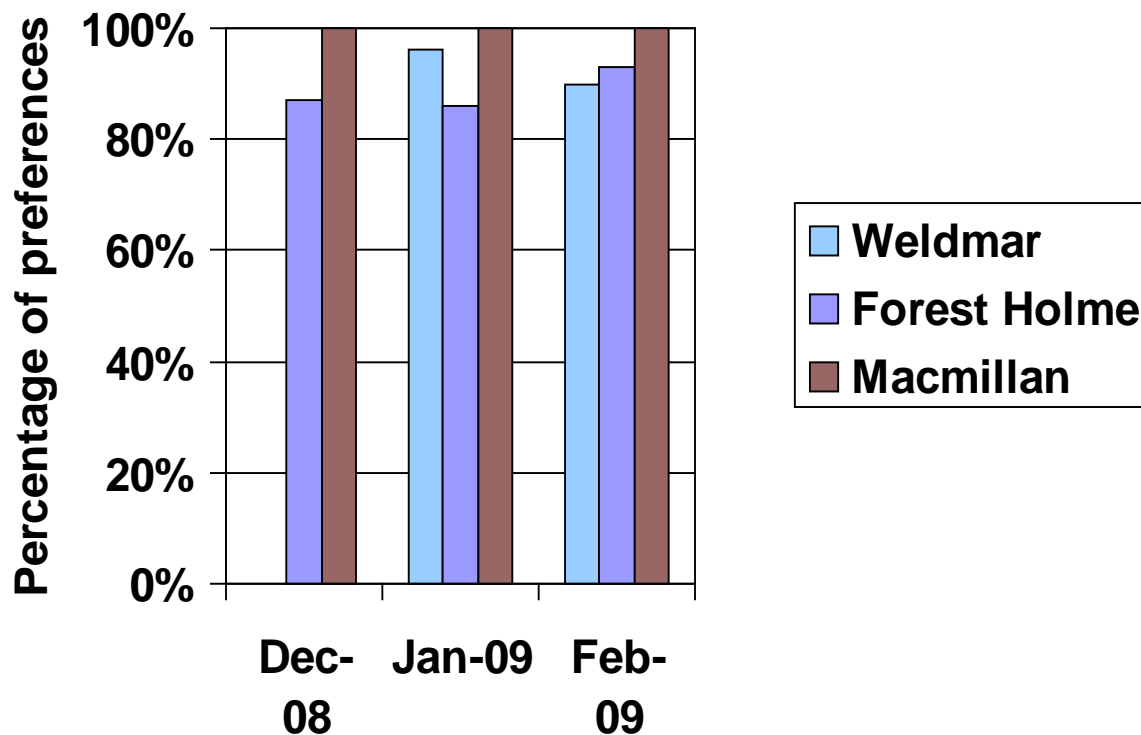
# Number of deaths



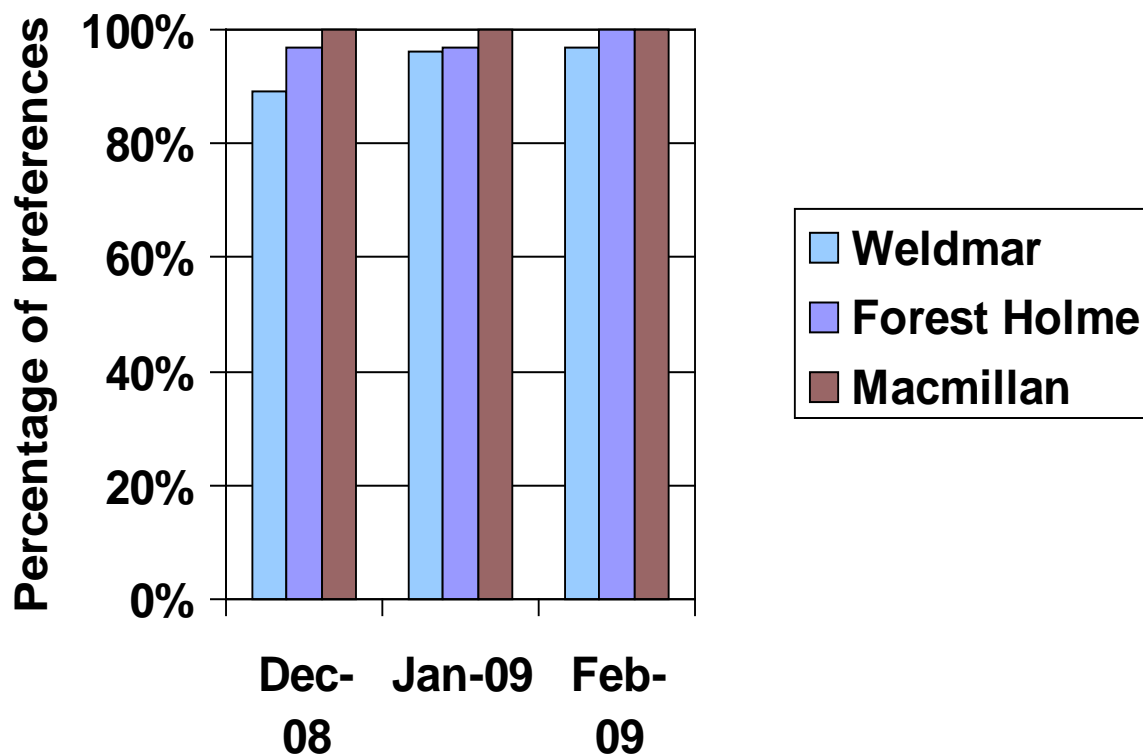
# Documentation of preferences of place of care or place of death



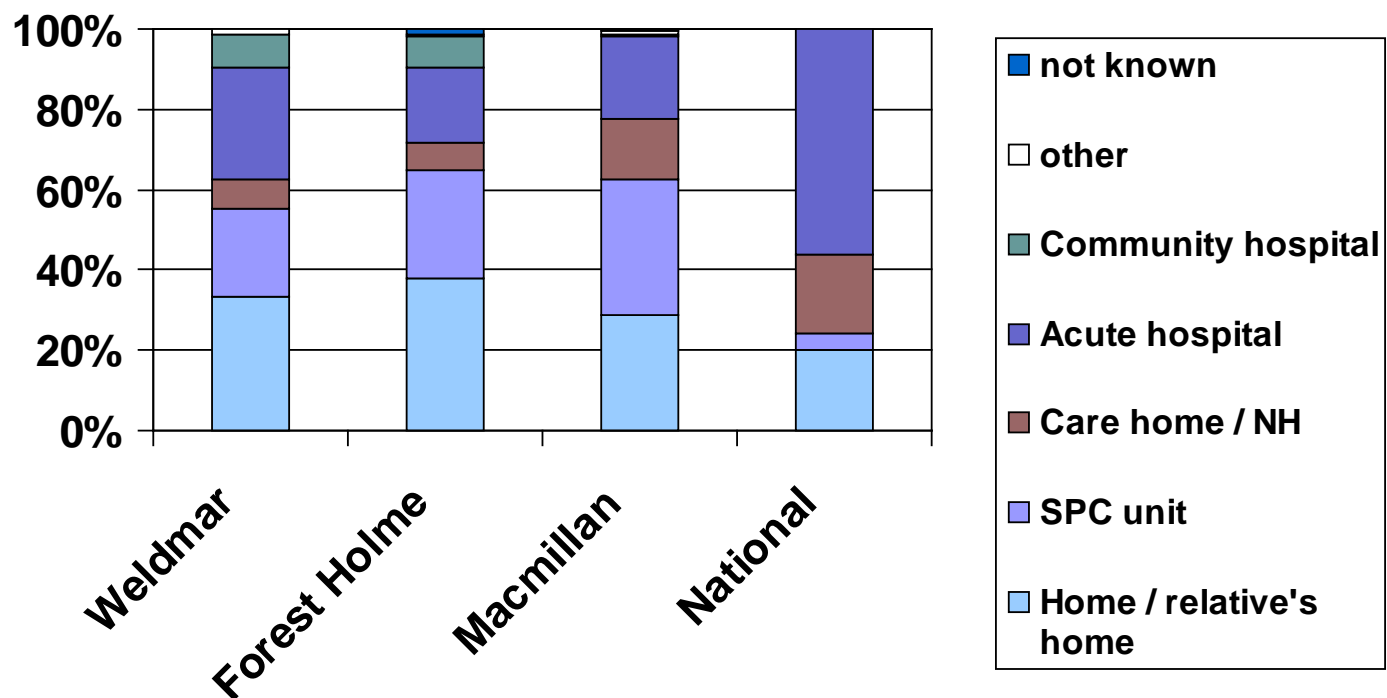
# Percentage of documented preferences which were in a standard place in the healthcare record



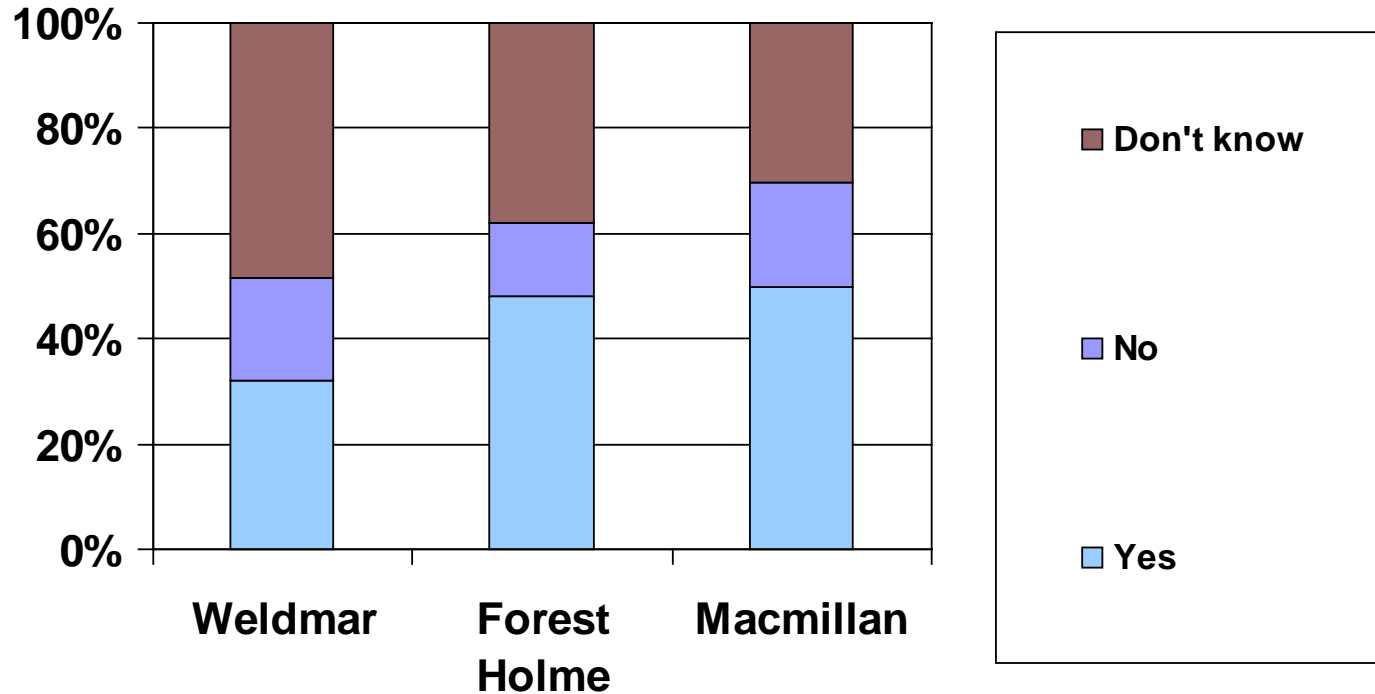
# Percentage of documented preferences which were dated



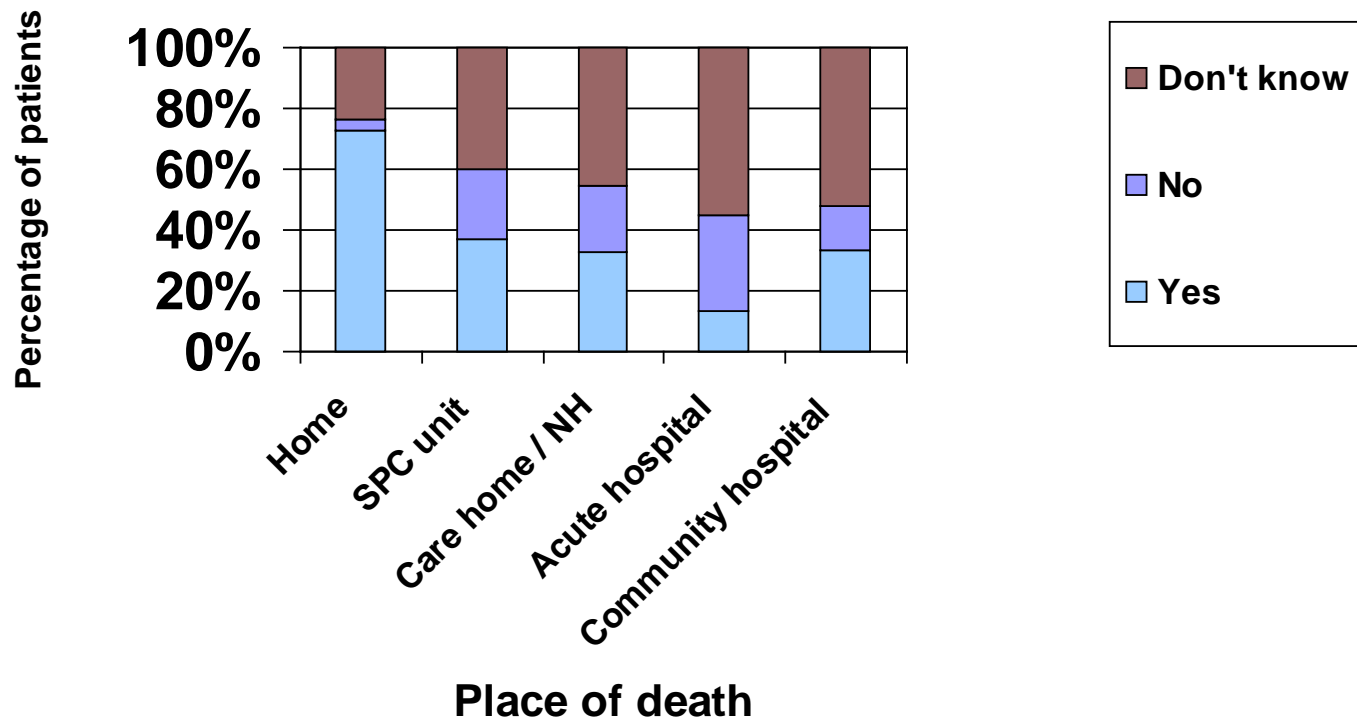
# Place of death (01/12/08 – 28/02/09)



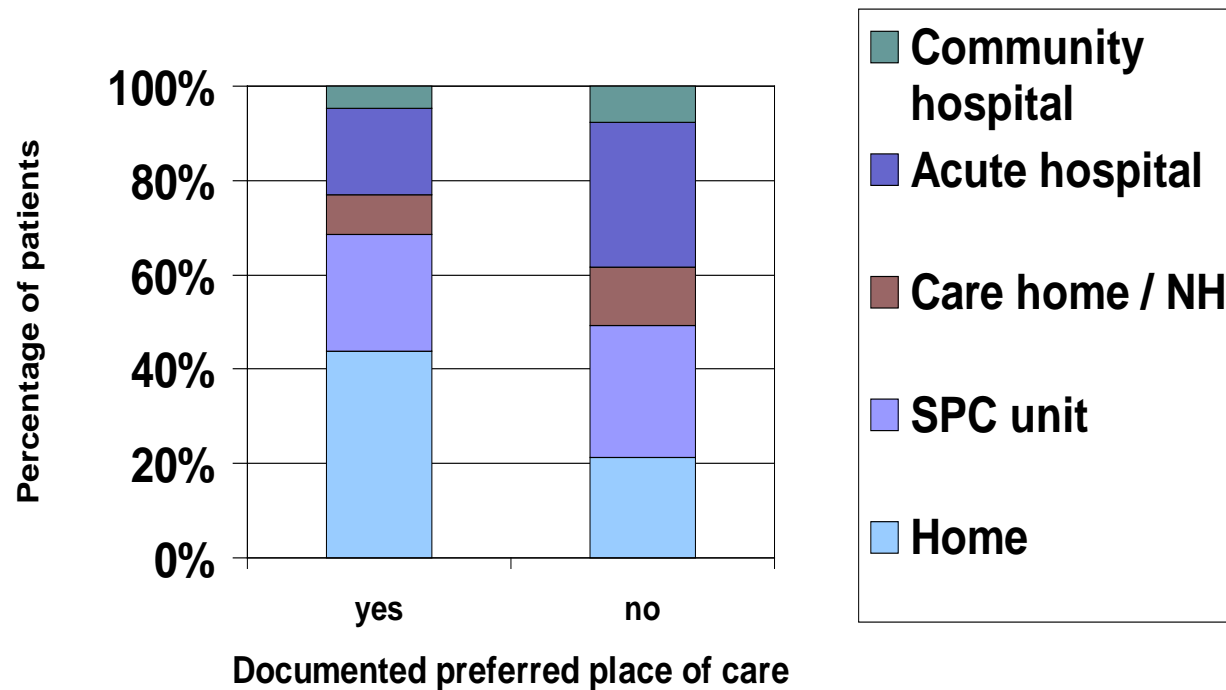
# Was the place of death in the most recently stated preferred place of care?



# Was the place of death in the most recently stated preferred place of care?



# Place of death – combined data



# Summary of results (1)

- A high proportion of documented preferences were in a standardised place in the healthcare record:
  - 100% Macmillan Unit
  - 63% Weldmar (0% in Dec 08 but 96% in Jan 09)
  - 89% Forest Holme
- A high proportion of documented preferences were dated:
  - 100% Macmillan Unit
  - 93% Weldmar
  - 98% Forest Holme

# Summary of results (2)

- There was an increase in the documentation of patients' preferences at the Macmillan Unit and Forest Holme during the audit period
  - increase in the number of discussions regarding patient preferences?
  - increase in documentation of discussions which were already taking place?

# Summary of results (3)

- Patients who died at home were more likely to have a documented preference for their place of care than those dying elsewhere.
  - More stable disease trajectory?
  - Better evidence of advance planning?
- Very few patients who died at home or in a community hospital had expressed a preference to die elsewhere.

# Summary of results (4)

- Patients who died in hospital were least likely to have a documented preference for their place of care.
  - Acute unexpected deterioration?
  - Less advance planning so admitted acutely?
  - Late referral to palliative care services?

# Discussion points (1)

- When should discussions take place?
- Who should take part in the discussions?
- How much detail should be included?
- Should we distinguish between preferred place of care and preferred place of death?
- How should discussions be documented and communicated?

# Discussion points (2)

- Should we document:
  - Ideal preference
  - Realistic choice
  - List of acceptable options

# Discussion points (3)

- Patient choice is important but there are other relevant considerations (clinical need, feasibility, justice)
- Place may not be the most important priority for the patient –  
    “**How** we die not **where** we die”

# Preferences and perceptions

- Change in preferences
  - “Where, given your present state, do you want to be?”
  - 100% (n=77) initially stated “home” but this fell to 54% at the final interview
  - “further requests for admission after this interview showed this trend continued”
- Perceptions of place of care
  - Family still perceive care having been at home, despite short terminal admission

Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? Pall Med 1994;8:183-96

# “I want to die at home”

- “Come what may, I want to end my days in my own home”

OR

- “When my days come to an end, I hope that it is in such a way that I am able to die at home”

Kirkham SR. Admissions and discharges. Pall Med 1994;8:181-2

# Location, location, location?

“If I could choose a place to die...  
it would be in your arms”

Derek and the Dominos, 1970

# Benefits of the audit

- Improved awareness of eliciting patient preferences
- Improved awareness of need to document preferences in standardised manner
- Network-wide approach and discussion
- Benchmarking of services
- End of Life Care Quality Markers
- Engagement with commissioners through End of Life Steering Group

# Limitations of the audit

- Data collection may be incomplete
- Audit of own practice for each service
- May not reflect true baseline of practice as prospective audit may have influenced the process (discussions and documentation)
- Proforma may not be suited to identifying nuances – place of death data easy to collect but much harder to classify preferences
- Some patients lacked capacity to express their preferences

# Potential harms

- Some staff may feel that they have to discuss preferred place of care with all patients, even though the patient may not wish to discuss at that time
- Overemphasis on **place** of death rather than **quality** of care or experience

# Conclusion

- Documentation of discussions was in a standard place in the record, and dated, for most patients with a documented preference.
- There is scope to improve the detail of the documentation of end of life discussions.
- A significant proportion of patients do not have a documented preference, and we should consider making the reason for this more explicit in the healthcare record.

# Recommendations

- Patients should be offered the opportunity to discuss their preferences for care when clinically appropriate
- Documentation of preferences for care at the end of life should be:
  - in a single agreed place in the healthcare record
  - dated
  - communicated to other professionals, with the patient's permission
- Documentation may include
  - Preference for place of care and acceptable alternatives (and situations in which alternatives would be acceptable)
  - Priorities such as being with family and friends, avoiding being a burden on family, dignity, symptom control, prolonging life as much as possible, availability of prompt professional help, etc.
- If discussions are not appropriate this should also be documented. For example:
  - Patient currently lacks the capacity to discuss this
  - Patient declines the offer of discussion for the time being
  - Not clinically appropriate to discuss at the time

# Acknowledgements

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