Evaluation of the Dying Matters GP Pilot Project
Aims of GP Pilot

• Aims to support GPs in their initial discussions about a patient’s wishes when the subjects of death, dying and bereavement arise
• Focus on raising awareness and on the knowledge and behaviour of GPs as key influencers
Objectives

• Raise the profile of Dying Matters Coalition

• Support GPs in their consultations with patients when the subjects of death, dying and bereavement arise

• Pilot communication materials and explore their utility from the GP and patient perspective
Success measures

- Number of patients with whom the GP has discussed end of life
- A GP’s confidence in initiating and having conversations with appropriate patients
- Action has been put into place as a result of the conversation
- GP rating on the usefulness of materials designed to assist with conversations
- Patient’s views on the helpfulness of materials
- Number of patients on the Palliative Register
Intervention

Workshops for GPs
Communication skills training

GP involvement in developing a suite of communications materials to support conversations about end of life
Methodology

Data collection

GP Questionnaire (pre and post pilot)
Conversation and Action Record Sheet
Death Audit

Patient Questionnaire
Results

Count
• Participants and responses

Conversations
• GP Confidence
• Actions

Communications
• Utility and helpfulness of communications materials

Audit
• Audit of patient deaths and palliative care registers
Count

Participants and responses
# Pilot participation

<table>
<thead>
<tr>
<th>Participants and responses</th>
<th>Number</th>
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<tbody>
<tr>
<td>Practices participating</td>
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<td>GPs participating</td>
<td>59 [63]</td>
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<td>GPs attended a preliminary workshop</td>
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<td>GPs returning a completed pre-pilot questionnaire</td>
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<tr>
<td>GPs returning a completed post-pilot questionnaire</td>
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<td>GPs returning completed both pre- and post-questionnaire</td>
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<tr>
<td>Practices undertaking &amp; returning a Death Audit</td>
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<tr>
<td>Records of conversations between GP and patient</td>
<td>155</td>
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<tr>
<td>GPs willing to be involved in ongoing work</td>
<td>40</td>
</tr>
<tr>
<td>Patient questionnaires returned</td>
<td>21</td>
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</table>
Conversations: GP Confidence

GP confidence in starting and having conversations about death, dying and bereavement
Change in all GPs’ self-rated confidence in starting and having conversations pre and post pilot

May 2010 ($n = 46$)

- Not confident
- Not very confident
- Confident
- Very confident

Sept 2010 ($n = 53$)

- Not confident
- Not very confident
- Confident
- Very confident
Change in GP confidence

Change in 41 GPs’ self-reported confidence in starting conversations about end of life (paired responses)

Very confident

Confident

Not very confident

Not confident

Pre-pilot confidence  Post-pilot confidence
Change in GP confidence

Change in 41 GPs’ self-reported confidence in having a conversation about end of life (paired responses)

Very confident
Confident
Not very confident
Not confident

Pre-pilot confidence
Post-pilot confidence
Conversations: Actions

GP records of conversations and actions
Age and gender

Number of patients (and carers) with whom GPs discussed end of life: 155

Gender

• 66 males, 84 females (gender of 5 patients not recorded)

Age of patient

• Median patient age - 76 years
• Sample range 74 years, IQR 22 years (ages of 12 patients not recorded)
Consultations

155 consultations with patients, family members and carers when GPs discussed end of life

<table>
<thead>
<tr>
<th>Consultation type</th>
<th>Number (n=139)</th>
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<tr>
<td>First with patient</td>
<td>87</td>
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<tr>
<td>Subsequent with patient</td>
<td>51</td>
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<tr>
<td>3rd Party (family member, carer)</td>
<td>16</td>
</tr>
<tr>
<td>Not recorded</td>
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Type of illness

Diseases and circumstances in patients, family members and carers with whom GPs discussed end of life

- Elderly, frail
- Dementia
- Cancer
- Vascular disease
- COPD
- Bereavement
- Other
- Not ill
Stage of illness

Stage of disease and circumstances in patients, family members and carers with whom GPs discussed end of life

Not recorded
Not ill
Early stage
Chronic
Advanced
Metastatic
End stage, terminal, palliative
Bereaved
Conversation triggers

The triggers for 155 conversations with patients, family members and carers when GPs discussed end of life

- Diagnosis: 8%
- Prognosis: 3%
- Deterioration in condition: 26%
- Patient question about future, death or dying: 14%
- Carer question about future, death or dying: 10%
- Patient in pain, distressed, anxious: 15%
- Death, bereavement: 16%
- Ageing: 14%
- Other: 3%
- Not recorded: 3%
Continuing the conversation

Response of patient to conversation

- 142 chose to continue the conversation
- 13 rejected the conversation

Nine times out of ten, patients will continue the conversation about end of life

Gender responses

- 79 females chose to continue the conversation, 5 rejected it. 58 males continued the conversation, 8 rejected it
- Among the 155 consultations when the GP discussed end of life, there are 11 ‘pairs’ of conversations when the same GP planned a subsequent conversation with the patient. In 3 of the 11 pairs, at first the patient had rejected the conversation about end of life.
Actions taken by GPs following a conversation about end of life

- Gave out leaflets
- Gave Out 5 Things To Do
- Gave Out Remember When We
- Gave out To Do List
- ACP
- Family conversation
- Subsequent conversation planned
- Preferred place of care recorded
- DNAR discussed
- DNAR recorded
- Patient put on EoLC register
- Palliative care started
- No action taken
- Other

Number of conversations vs. Actions recorded following a conversation about end of life
Other actions following a conversation

A significant number of ‘other’ actions were recorded. Most frequently these included:

- Discussing patient’s pain and discomfort, reviewing pain management
- Treatment and medication review, symptom control
- Requesting involvement of District Nurse(s) and others e.g. MacMillan Nurse, Night Sitters to visit, to discuss options and provide information and support
- Referral or offer of support to family members and carers
Communication

Utility and helpfulness of communication materials – views of GPs and patients

Impact of communication skills training workshop
Poster

Rating of 53 GPs on the usefulness of a poster

Number of GPs

<table>
<thead>
<tr>
<th>Rating</th>
<th>Starting conversations</th>
<th>Having conversations</th>
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<tr>
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<td>3</td>
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<td>Useful</td>
<td>17</td>
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<td>18</td>
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<td>Not useful</td>
<td>5</td>
<td>4</td>
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<tr>
<td>Did not use this</td>
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<td>1</td>
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Postcard

Rating of 53 GPs on the usefulness of a postcard

Number of GPs

<table>
<thead>
<tr>
<th></th>
<th>Starting conversations</th>
<th>Having conversations</th>
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<tbody>
<tr>
<td>Very useful</td>
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<td></td>
</tr>
<tr>
<td>Useful</td>
<td>20</td>
<td>15</td>
</tr>
<tr>
<td>Not very useful</td>
<td>15</td>
<td>10</td>
</tr>
<tr>
<td>Not useful</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Did not use this</td>
<td>5</td>
<td>4</td>
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</table>
Leaflet: Five Things To Do

Rating of 53 GPs on the usefulness of Five Things To Do

- **Very useful**
- **Useful**
- **Not very useful**
- **Not useful**
- **Did not use this**

Bars for starting conversations and having conversations.
Leaflet: Remember When We

Rating of 53 GPs on the usefulness of Remember When We

- **Very useful**
- **Useful**
- **Not very useful**
- **Not useful**
- **Did not use this**

Legend:
- Blue: Starting conversations
- Red: Having conversations
Leaflet: To Do List

Rating of 53 GPs on the usefulness of To Do List

- **Very useful**
- **Useful**
- **Not very useful**
- **Not useful**
- **Did not use this**

**Starting conversations**

**Having conversations**
<table>
<thead>
<tr>
<th>GP response</th>
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<td>7</td>
<td>3</td>
<td>2</td>
<td>1</td>
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<tr>
<td>Not sure</td>
<td>18</td>
<td>19</td>
<td>14</td>
<td>13</td>
<td>6</td>
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<tr>
<td>Did not use</td>
<td>4</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Some GP comments on materials

“They acted as a reminder to consider initiating a conversation, so were helpful for that”

“I feel that by having the leaflets in the waiting room this gave people the opportunity to think and have "permission" to talk about death with clinicians and their family members I thought that the leaflets were practical, clear and helpful”

“Quite often I was on home visits with the out of hours and didn't have the leaflets to hand”

“The three leaflets complement each other and take care of patient and the carer”

“Found leaflets particularly of use for those supporting dying relatives who came in for advice about what to do and what to say “
Some GP comments on materials

“Tend to know the patients well and family by the time 'the discussion' takes place - leaflets often superseded by events”

“Think the ‘to do list’ leaflet has a more subtle approach to discussions and suited my patients better than the '5 things to do before I die' leaflet”

“No-one commented on the posters. I still feel though poster does give permission to bring it up”

“...could be combined as one leaflet, mostly same message”

“I wonder if a DVD for those who do not like to read or cannot read [would be useful]”

“Small print - most patients were elderly and not sure if they could read fine print every time “
Patient views on communication materials

Views of 21 patients on the helpfulness of communication materials

<table>
<thead>
<tr>
<th>Patients views</th>
<th>Number of patient responses</th>
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<td>Very helpful</td>
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<tr>
<td>Helpful</td>
<td>7</td>
</tr>
<tr>
<td>Not very helpful</td>
<td>5</td>
</tr>
<tr>
<td>Not helpful</td>
<td>3</td>
</tr>
<tr>
<td>Did not see this</td>
<td>2</td>
</tr>
</tbody>
</table>

- **5 Things To Do**: 8 responses
- **Remember When We**: 2 responses
- **To Do List**: 5 responses
- **Poster**: 4 responses
- **Postcard**: 3 responses
Patients comments

Example of a comment on Five Things To Do

“The leaflet is very clearly laid out. A useful check list. Don't say anywhere if it’s available in other formats”

…and Remember When We

“Quite clearly set out. It is a very difficult subject to talk about but it has made me realise the importance of doing so”
GPs reported displaying the materials in their own consultation rooms and in waiting and reception areas

• The waiting room was the most common choice for displaying posters and postcards
• Almost two thirds of GPs chose to display the leaflets in their own consultation rooms
Impact of workshop on GP behaviour

Excellent compliance and commitment
92% of GPs who attended the workshops completed all pre and post pilot activities

Only GPs who did not attend the workshop commented on being less able to identify the most appropriate material for different audiences

“I only used one”

“have not used pack very much”

“all seem quite similar”

“Initially confusing as such a variety ..could this be more immediately clear?”
Audits

Audit of patient deaths and palliative care registers
Death Audits

• Practices undertaking a Death Audit
  (14 Death Audits undertaken using similar template*, 4 Death Audits not directly comparable)

• Deaths reviewed in all 18 Death Audits
  (163 deaths in directly comparable Audits and 89 deaths in non-directly comparable Audits)

• Individuals may have benefited from palliative care but had not been identified as such at the time of their death

* 14 Practices chose to use a Death Audit template: reviewing 10 most recent deaths, noting patients age, gender, diagnosis prior to death, if patient was already on the End of Life care register/receiving palliative care & if the patient would have benefited from being placed on the EoLC register/receiving palliative care
GPs comments on Death Audits

“This audit has made me think more carefully about identifying palliative care patients with other diseases apart from cancer”

“Aside from placing on the ‘palliative care register’...preferred place of death..is an important piece of information”

“...we need to think more broadly about the types of patients who we add to the register”

“home death rate of 33% ...compares very favourably to national statistics”
GPs comments on Death Audits

“this audit may help us to include more patients with a non-cancer diagnosis”

“It goes without saying that good clinical care at the end of life can be provided whether a patient is put on a list or not”

“the difficulty would have been to decide when [the patient] became palliative”
Summary
Another look at success measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>✔️</th>
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<tbody>
<tr>
<td>Number of patients with whom the GP has discussed end of life</td>
<td></td>
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<tr>
<td>A GP’s confidence in initiating and having conversations with appropriate patients</td>
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<td>Action has been put into place as a result of the conversation</td>
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<td>Patient’s views on the helpfulness of materials</td>
<td></td>
</tr>
<tr>
<td>Number of patients on the Palliative Register</td>
<td></td>
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</tbody>
</table>
Pilot summary

Some limitations of the pilot to bear in mind:

• Practices and GPs opted-in (self-selected)
• 41 GPs out of a total of 59 participating in the pilot completed and returned both pre and post pilot questionnaires
• Conversation and action records were completed and returned by 30 GPs from 21 practices (out of 59 GPs in 24 practices participating) so the actions do not fully reflect practice in all practices or conversations and actions of all GPs participating in the pilot
• 14 of 18 Death Audits were undertaken using a similar template - not all audit data is directly comparable
Confidence

• In the pre-pilot stage, 60% of GPs rated themselves either ‘not confident’ or ‘not very confident’ in initiating conversations about end of life and 33% rated themselves either ‘not confident’ or ‘not very confident’ when having conversations.

• Post-pilot, 86% of GPs rated themselves as being ‘confident’ or ‘very confident’ when starting conversations about end of life and 90% rated themselves as ‘confident’ or ‘very confident’ when having conversations.
Change in confidence

• GP’s self-reported confidence in initiating conversations shifted from ‘not very confident’ to ‘confident’. The probability that this change in GP’s confidence is due purely to chance is extremely small ($P > 0.001$)

• Whilst a larger proportion of GP’s described themselves as confident in having conversations in the pre-pilot phase, a smaller but significant increase in their post-pilot confidence was still observed. The probability that this change is due purely to chance is also extremely small ($P > 0.001$)

This suggests, with a comfortable degree of confidence, that participating in this pilot increased GPs confidence in initiating and having conversations about end of life
Conversations

• Half of all conversations were triggered by either a question from a patient or carer, or a deterioration in a patient’s condition
• 58% of GPs conversations were held with patients who were in an advanced, metastatic or end stage of disease
• 8% of conversations were triggered by a bereavement
• 50% of patients, with whom GPs discussed end of life, have cancer, 20% are elderly or have dementia
• Nine times out of ten, a patient will continue the conversation about end of life
• Following 11 of the conversations, GPs planned and carried out a subsequent conversation about end of life (in three cases the initial discussion had been rejected by the patient)
“Since participating in this pilot I feel a lot more confident about talking to patients about dying. Thank you.”

“Being part of this pilot project made me focus and think about initiating discussions about dying. Quite often I initiated the conversation about how they were coping and their thoughts “
Actions

Following 69 out 155 (44%) conversations with patients about end of life, the GP had a conversation with family members.

Following a conversation about end of life, GPs were most frequently:
- Recording the patient’s preferred place of care (30%)
- Giving information (the leaflet ‘To Do List’ - 27%)
- Discussing and recording patients’ wishes regarding resuscitation (25%)
- In 27 of the 155 conversations, DNAR was discussed and subsequently DNAR recorded in the patient’s notes.
Communication

• GPs rate the leaflets ‘Remember When We’ and ‘Five Things To Do’ as useful when starting and having conversations about end of life
• GPs rate the leaflet ‘To Do List’ as the most useful and this is the leaflet they are most likely to recommend (81% would recommend it)
• GPs rate the postcard as the least useful material
• Patients rated all leaflets, the poster and postcard as either very helpful or helpful
Death Audits

- 18 practices undertook a Death Audit as part of the GP Pilot Project and 252 deaths were reviewed in the Audits.
- Having undertaken an Audit, several practices commented that the process helped to confirm GPs were appropriately placing patients on the End of Life care register.
- Of the 252 deaths reviewed in the Audits, there were 26 (10%) individuals who may have benefited from palliative care but who had not been identified as such at the time (for a number of reasons).
- Practices undertaking a Death Audit commented on being able to identify an area of practice for further exploration or for improvement.
GP Pilot Project Evaluation