Appendix 3: The national workshop

Date and venue: Friday 26th June 2009, 10am- 4pm
Salisbury Green, University of Edinburgh

Agenda:

<table>
<thead>
<tr>
<th>Time</th>
<th>Activities</th>
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<tbody>
<tr>
<td>9.30</td>
<td>Registration and welcome</td>
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<tr>
<td>10.00</td>
<td><strong>Presentation: Overview of findings of the research</strong></td>
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<td>11.30</td>
<td>Coffee break</td>
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<tr>
<td>12.00</td>
<td><strong>Morning discussion group</strong></td>
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<td>13.00</td>
<td>Sandwich lunch</td>
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<tr>
<td>14.00</td>
<td><strong>Feedback from morning discussion groups</strong></td>
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<td>14.10</td>
<td><strong>Afternoon discussion groups</strong></td>
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<tr>
<td>15.10</td>
<td>Tea break</td>
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<tr>
<td>15.30</td>
<td><strong>Feedback from afternoon discussion groups</strong></td>
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<tr>
<td>15.40</td>
<td>Closing remarks and thanks</td>
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Participants

<table>
<thead>
<tr>
<th>Group</th>
<th>Name</th>
<th>Delegate</th>
</tr>
</thead>
</table>
| 1 Needs | Group leaders | Researcher  
Palliative care consultant |
| Group participants |  | Two member of the Lay Advisory Group  
Hospital Chaplain  
Pharmacist  
Researcher: Cambridge Breathlessness intervention team  
Social Services |
| 2 Services  
(Patients) | Group leaders | GP with respiratory interest  
Respiratory specialist nurse |
| Group participants |  | Member of the Lay Advisory Group  
Researcher: TELESCOT programme  
Palliative care nurse specialist  
LTC and Palliative care clinical lead  
Allied Health Professional manager |
| 3 Services  
(Professionals) | Group leaders | GP with palliative care interest  
National respiratory training organisation |
| Group participants |  | GP: TELESCOT programme  
Long-term conditions service co-ordinator  
Respiratory physiotherapist |
| 4 Policy  
Framework | Group leaders | Academic GP  
Researcher (palliative care) |
| Group participants |  | Member of the Lay Advisory Group  
CSO  
Department of Health: COPD NS  
BTS/GPIAG IMPRESS group  
GP and Scottish Government  
Director, Scottish partnership for palliative care |
Morning discussion groups. Group 1: Needs

Objective 1. Identify the clinical, information, psychosocial and spiritual needs of patients and their key informal carers as their disease progresses over time

The patients and carers in our study coped with a wide range of physical, social, psychological and spiritual needs, which severely restricted their lives. The key needs that we identified were a range of disabling symptoms (especially breathlessness and chest infections), loss of social functioning, social isolation, limited information, depression. Inappropriate housing and social circumstances were major problems which added considerably to the burden of disease, and which they felt powerless to influence (see briefing document for more detail)

- Does this picture fit with your experience of the needs of people with very severe COPD?
  - Is there anything important from your experience that you think we may have overlooked?
  - Can you give examples that support our findings – or refute them?

A theme that became apparent from the earliest interviews with the patients was a sense of ‘passive acceptance’ in the face of severe disease and social difficulties

- Does this theme of ‘passive acceptance’ resonate with your experience?
  - Why do you think this might be?
  - Can you give examples that support, or refute our conclusion?
  - How does this ‘passive acceptance’ affect the needs, or the expression of those needs?

The patients found it difficult to tell the ‘story’ of their COPD. They could not identify a beginning, the middle was an unstructured series of acute exacerbations with an end that is not anticipated from the beginning and could not be predicted. The narrative was thus never distinguished from the life story and natural aging. Although the participants in our study all recognised the current ‘reality’ of their illness, the lack of story, the causal link with lifestyle and the lifetime trajectory meant that in many ways COPD was perceived as a ‘health problem that was not a real illness’

- Do you agree with this interpretation?
  - Can you give examples from your experience that confirm or refute our interpretation?
  - How does this affect the needs, or the expression of those needs?
  - What are the ‘milestones’ that, in your experience, mark the transition to a ‘real illness’?
  - How does/should this impact on how services are provided?
Morning discussion groups.  Group 2: Services (patients/carers)

Objective 2a. Describe and understand patients’ and informal carers’ utilisation of health, social and voluntary sector services.

The participants had experience of a wide range of health, social and voluntary sector services, few of these adequately met their needs as they were generally fragmented and difficult to access. Medical services were generally reactive, and although those with access to specialist respiratory nurse services appreciated the support, on-going care was limited by heavy workloads. Hospice day care, pulmonary rehabilitation and voluntary support groups were much appreciated by the few patients who attended them. (see briefing document for more detail)

• Does this picture fit with your experience of the services used by people with very severe COPD?
  o Is there anything important from your experience that you think we may have overlooked?
  o Can you give examples that support our findings – or refute them?

A theme that became apparent from the earliest interviews with the patients was a sense of ‘passive acceptance’ in the face of severe disease and social difficulties

• Does this theme of ‘passive acceptance’ resonate with your experience?
  o Why do you think this might be?
  o Can you give examples that support, or refute our conclusion?
  o How does this ‘passive acceptance’ affect the attitude to, and utilisation of services?

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• Do you agree with this interpretation?
  o Can you give examples from your experience that confirm or refute our interpretation?
  o How does this affect the utilisation of services? Does this apply equally to healthcare, social and voluntary services?
  o What are the ‘milestones’ that, in your experience, mark the transition to a ‘real illness’?
  o How does/should this impact on how services are provided?
Morning discussion groups. Group 3: Services (professionals)

Objective 2b. Describe and understand professionals’ perception of the challenges of providing care for these patients and informal carers

The challenges for professionals mirrored those for patients and carers—they also often feel frustrated, hopeless, lost and abandoned, unable to make things happen—though there was also discussion about new developments and signs of hope. All the clinicians struggled with the problem of the uncertain prognosis, and had great difficulty recognising and managing the transition to palliative care. Despite recognising that their patients had very severe COPD, they did not know when to include these patients on their palliative care registers and were not sure how to apply the ‘Gold Standard Framework’. Other key challenges included difficulty working within a regime of fragmented and reactive care, and practical difficulties related to lack of time, over-large caseloads and communication problems (see briefing document for more detail)

- Does this picture fit with your experience of the services provided for people with very severe COPD?
  o Is there anything important from your experience that you think we may have overlooked?
  o Can you give examples that support our findings—or refute them?

A theme that became apparent from the earliest interviews with the patients was a sense of ‘passive acceptance’ in the face of severe disease and social difficulties

- Does this theme of ‘passive acceptance’ resonate with your experience?
  o Why do you think this might be?
  o Can you give examples that support, or refute our conclusion?
  o How does this ‘passive acceptance’ affect how services should be provided?

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- Do you agree with this interpretation?
  o Can you give examples from your experience that confirm or refute our interpretation?
  o How does this affect the utilisation of services? Does this apply equally to healthcare, social and voluntary services?
  o What are the ‘milestones’ that, in your experience, mark the transition to a ‘real illness’?
  o How does/should this impact on how services are provided?
Morning discussion groups.  Group 4: Needs, services and policy

Objective 3: Integrate the perceptions of patients, informal carers and professionals
The patients and carers reported a wide range of physical, social, psychological and spiritual needs, many of which were echoed by the professionals. The key needs that we identified were a range of disabling symptoms (especially breathlessness and chest infections), loss of social functioning, social isolation, limited information, depression and poor housing.

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• What are the policy and framework implications of this picture of a mismatch between extensive need and fragmented service provision for people with very severe COPD?
  o Is there anything important from your experience that you think we may have overlooked?
  o Can you give examples that support our findings— or refute them?

A theme that became apparent from the earliest interviews with the patients was a sense of ‘passive acceptance’ in the face of severe disease and social difficulties

• Does this theme of ‘passive acceptance’ resonate with your experience?
  o Why do you think this might be?
  o Can you give examples that support, or refute our conclusion?
  o What are the implications of this ‘passive acceptance’ for the policy and frameworks underpinning service provision for people with very severe COPD?

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• Do you agree with this interpretation?
What are the implications of this for the policy and frameworks underpinning service provision for people with very severe COPD?

Does this apply equally to healthcare, social and voluntary services?

What are the ‘milestones’ that, in your experience, mark the transition to a ‘real illness’?

Afternoon discussion groups (all four groups)

We are concerned that the study findings should translate into practical outputs. We are seeking ideas that could improve the lives of people with very severe COPD.

1. Brainstorm suggestions for new interventions/services/policies/resources. These could be policy changes, supportive service, information, and could apply in the healthcare, social, or voluntary sector. They could be anything from a major new service to a minor tweak to an existing service. At this stage do not feel constrained by practicalities such as time, money and resources!

2. Focus on one major idea (even if there are resource implications) that could make a significant difference to the lives of people with severe COPD. Produce an outline development/implementation plan including:
   - A description of the idea and how it might be developed and implemented
   - Who, or which services, would need to be involved
   - Consider the resource implications including personnel, training needs, national and local incentives that might be needed?
   - If this idea were to be developed/implemented, what would be the outcomes we should measure in order to demonstrate whether the idea was effective?

3. Identify a ‘quick fix’ that for minimal time, money and resources could improve life for people with very severe COPD. Outline the idea and how it might be developed and implemented