Report of the Workshop on Draft NICE Guidelines on Care of the Dying Adult with Users and Carers

Monday 21st September 2015
10.30am – 13.00am
Acknowledgements

AIIHPC would like to thank all those who attended the workshop and gave their personal contributions on the day which were valuable to discussions on the day and to the completion of this report. AIIHPC would also like to thank the Patient Client Council in Northern Ireland for helping to contact people interested in attending.
Overview
Through membership of the Northern Ireland’s Living Matters Dying Matters Implementation Board, All Ireland Institute of Hospice and Palliative Care’s (AIIHPC), Director offered to host a workshop for users, carers/ previous carers or citizens with an interest to consider important aspects of care in the last few days of life.

Following the withdrawal of the Liverpool Care Pathway, National Institute of Health and Care Excellence (http://www.nice.org.uk/), the organisation with responsibility for developing guidance and quality standards in social care in the UK are progressing the development of the Draft Guidelines on Care of the Dying Adult.

An invitation was issued to all the members of AIIHPC’s user / carer panel, Voices4Care, and to members of the Patient and Client Council through the Public Health Agency in Northern Ireland to discuss the issues that matter most for patients and their families in the last days of life.

AIIHPC facilitated a workshop to discuss matters related to the draft NICE Guidelines on Care of the Dying Adult. Seventeen users and carers took part. Four participants were members of AIIHPC’s user/carer panel Voices4Care with the remaining being members of the Patient Client Council in Northern Ireland. Two observers attended one from the Patient Client Council and the Public Health Agency.

Feedback from the day, summarised below, is provided to Northern Ireland’s Living Matters Dying Matters Implementation Board. This feedback will also help inform AIIHPC’s Palliative Hub’s End of Life stage on the Palliative Hub – Adult website.

Recommendations
From the workshop discussions and feedback, AIIHPC would like to offer the following recommendations to Living Matters Dying Matters Implementation Board for their consideration

- Develop and deliver adequate guidance and training to health and social care professionals on content of guidelines.
- Roll out training programme to improve communication skills tailored to care of the dying for all health and social care professionals.
- Bereavement should be included in final version of the Guidelines or supplementary guidance should be produced.
- Guidelines should be considered as guiding principles underpinning a tailored and personalised approach to care of each person as an individual informed by clinical judgement.
- Deliver a multi-channel, accessible public information campaign to promote awareness of issues related to people in the last days of life.
Session 1: Personal experiences and perspectives on End of Life Care

During the first session, workshop participants were asked to reflect on what they felt were the most important issues for the last days of life. Good and bad issues were to be considered and words to describe them were posted on a flipchart for discussion in small groups.

The importance of good communication was most significant theme to emerge from the words and the subsequent discussion. Good communication underpinned the concept of realising a good and peaceful death and also in ensuring that families, friends and carers are included and supported in last days of someone’s life and during their grieving after death.

The word cloud below details the words which participants highlighted around their own experiences and reflections below:
Session 2: Draft NICE Guidelines on Care of the Dying

A presentation was given on the draft NICE Guidelines on Care of the Dying highlighting the six key areas they covered:

1. Recognising when people are entering last days of life
2. Communication
3. Shared-decision making (Patient, Professional & Family)
4. Medications that may be required (Anticipatory)
5. Maintaining fluid intake
6. Management of Symptoms

The participants discussed the content of the guidelines under semi-structured headings.

Does your table feel the issues raised in the presentation echoes the conversation this morning?

Participants were asked whether they felt the issues raised in the presentation echoed the conversation in the first session. Participants felt that issues discussed in the first session would be addressed by the areas outlined in the draft NICE guidance with some identifying the need for an individualised approach which is responsive to the needs of each person and their family.

Unprompted comments gave recognition to the instrumental role of the relationship between clinical staff and family in the last days of a person’s life. In addition, participants felt that issues that often arise are around effective communication. Participants felt effective communication could be addressed if the Guidelines are implemented and adhered too. One participant emphasised the need for adequate training to ensure the effective roll out of the guidelines in terms of ensuring effective communications and involvement of family members.

What seems to be missing that your table feels needs attention?

Participants identified that bereavement was not included in the guidelines.

Additional issues which were raised were from a systems point of view rather than specifically from the content of the Guidelines. Participants felt that they needed to develop a general awareness of how the system works. In addition, others wanted to understand the process of recording and communicating information related to an individual’s care and how they could access this.

Some wished to understand more clearly how to access information related to the planning of care and treatment in the broader context of issues related to shared-decision making.

Many of the participants felt that clear and consistent record keeping and the communication of information had central importance in ensuring the patient is treated as an individual ensuring both an individual and their family is included and informed at all stages of the dying process.

Cultivating sensitivity and compassion was therefore identified as essential for staff training needs. The issue of anticipatory medication and other matters related to symptom management for example the issue of constipation had not been previously considered by a significant number of the participants. A number of participants had not previously considered the inclusion of bereavement but many felt this should be integral to future guidance.
Which, if any, of the 6 Key areas are new and useful information for you?
When asked what other questions were raised the two most salient issues to emerge again related to communication and management of symptoms. One participant emphasised the need for open and honest communication between patient and health and social care professionals. One participant clearly linked the issue of effective communication from clinicians with the desire to be given explanations about why medications change, why and what anticipatory prescribing might entail and why this important in ensuring that pain is managed effectively and that the whole person (physical, emotional and spiritual) can be looked after.

Session 3:
In the last session of the morning, participants were asked to complete a short questionnaire on how they feel it would best to communicate this kind of information. A summary of the responses are below:

When it would be most appropriate to share information related to Guidelines for care of the dying?

![Bar Chart]

Additional Comments
One participant queried as to whether you would want this type of information when one is dying, whereas another felt it would appropriate for the guidelines and associated information to be communicated at the time of diagnosis by a health and social care professional.
I would prefer to get this type of information from:

![Bar graph showing preference for information sources]

**Additional Comments**
One participant felt that there should be multiple methods / channels of communication adopted in order to reflect the diversity of the population. Another participant stated that the communications should be disabled friendly.

There was a lack of consensus in terms of the timing of the delivery of information with one respondent believing the information should be provided early as soon as someone would apply for critical illness cover for example.

People’s preferences for who should deliver this information emerged in the comments also with some preferring it to come from their General Practitioner in the context of available support with others preferring a personal discussion with Consultant or health and social care professional at the time of diagnosis. Another though stated the preference to have information related to care of the dying in the last days of life delivered through a partner or close friend.

**Next Steps**
This report will be shared with the Living Matter Dying Matters Implementation Board. The NICE Guidelines will be launched on the 16th December 2015.

A further piece of work around co-produced public information to support the NICE Guidelines is being considered. The themes and information within this report will help support this development. Members who attended this workshop may be invited to contribute to future work.
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<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>10.00 – 10.30</td>
<td>Registration</td>
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<tr>
<td>10.30 – 10.45</td>
<td>Welcome &amp; Introduction</td>
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<tr>
<td>10.45 – 11.30</td>
<td>Discussion on personal experiences or perspectives and feedback on care at the end of life.</td>
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<tr>
<td>11.30 – 12.15</td>
<td>Presentation and discussion on draft content of NICE “Care of the Dying Adult” Guidelines</td>
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<td>12.15 – 12.25</td>
<td>Comfort Break</td>
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<td>12.25 – 12.55</td>
<td>Discussion on methods of communicating future guidance</td>
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<td>12.55 - 13.00</td>
<td>Evaluation</td>
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