

## Abstracts

identity and the day- to -day life in the hospice. Responses to the film qualify it as an art based research as watching it enables learning, enhances and challenge audiences' understanding and perception of death and dying.

Key themes that patients raised were their need to be seen as individuals rather than patients and their desire to challenge pre-conceptions that dying patients are weak, vulnerable and passive.

**Conclusion:** Making a film within a hospice has enabled patients to have a voice as individuals and challenge current perceptions of the dying patient.

Wide distribution of the film through television and cinema will encourage public debate across all medias, challenging assumptions about death, dying and the day-to-day life in a hospice.

## Conference Papers 4

### 015 COLLABORATIVE LEADERSHIP - WORKING IN PARTNERSHIP TO IMPROVE THE DESIGN AND DELIVERY OF PALLIATIVE AND END OF LIFE CARE ACROSS EAST LONDON

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**Background** In 2012, St Joseph's Hospice and Marie Curie pro-actively formed a strategic partnership. Unified by the shared goal of enabling more people to achieve choice at the end of life, the partnership provides the required leadership, to facilitate change and develop across EoLC services.

**Aim** The partnership aims to:

- improve performance across the East London EoLC system;
- develop a stronger EoLC voice locally through reforms across health and social care.
- Meet the complex and growing demand for services through collaboration, innovation, and community engagement.

**Approaches used** The partnership identified a number of themes that collaborative leadership could benefit from: Urgent Care; Care in the last days of life; Support for Families and Carers; Coordination of Care.

The partnership has been driving change and stimulating innovative solutions through:

- Bringing together stakeholders from across health and social care, commissioning teams and service users to develop a shared commitment for change.
- Designing new services to better meet local need with multi-borough, multi-disciplinary teams.
- Developing robust business cases to support and inform commissioning.

**Outcomes** Outcomes of the partnership :

- Raising the profile of EoLC across East London, and placing the hospice at the centre of developments.
- Design of an ambitious EoLC Coordination Centre.
- Undertaking detailed baseline mapping of the support available for families and carers.
- Hosting stakeholder and community events to raise an understanding of needs of families and carers, laying the foundations for change and development.

**Application to Hospice practice** The value of partnership work to support hospice development :

- The importance of hospices taking a pro-active leadership role in forming networks across East London.
- The value of sharing resources, expertise, learning, and networks to make improvements and facilitate the redesign of care.
- The recognition of the contribution that palliative and end of life care can make to the wider health economy.

### 016 BARNSELY HOSPICE - "MAPPING OUR COMMUNITIES"

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Barnsley Hospice offers a broad range of services to an adult population of approximately 177,000 individuals across 127 square miles of the borough.

As in many hospices, there exists a wealth of data that, if extracted, analysed and presented in the appropriate manner, has the potential to streamline operations, help focus valuable resource and improve outcomes across all areas. A recent move by the Local Authority to create six new 'Area Councils' with localised budget and decision-making responsibilities has been seen by the hospice as an opportunity to take a more focused approach on community engagement with a key aim being to extract and merge relevant data to deliver an overall 'view' of demographics, patient activity, fundraising and key stakeholders within each area.

In order to engage with our communities, the hospice primarily needed to engage itself in the process and value of data. Data from different systems was cleansed, refined and combined into a single set and uploaded into the Google Fusion Tables product in order to display it visually on a Google Map. In addition to this, additional datasets were mined from public sites such as Health & Social Care Information Centre in order to enrich and validate the view. The map is layered, allowing various elements to be enabled/disabled according to what the individual viewer wishes to see.

The opportunity to interact with data in a 'visual' way has realised several key outcomes with some specific examples including:

- Enhanced engagement in data across the hospice
- Identifying geographic areas that may need additional focus on patient referrals
- Defining targeted fundraising activity
- Producing an overall picture of activity across the different areas

The tools used are, at the time of writing, currently free for non-profits and can significantly assist hospices to realise the potential of the information they hold.

### 017 ANY QUALIFIED PROVIDER - A POSITIVE EXPERIENCE FOR A HOSPICE LYMPHOEDEMA SERVICE

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**Background/context** Historically the hospice had provided a lymphoedema service for patients who had predominantly

cancer related lymphoedema. However, over time it became apparent that the condition for many of these patients had stabilised and they were living with chronic lymphoedema. This posed a dilemma for the hospice as to whether hospice funds should continue to be used to treat this category of 'non-palliative' patients. The hospice undertook a detailed activity analysis of the lymphoedema service and presented this to the NHS commissioning managers. This led to the hospice working with one PCT area to establish an NHS community based non-palliative lymphoedema service. A further, newly formed CCG decided to take a different route to offer a non-palliative service under an Any Qualified provider (AQP) contract.

**Aim** To establish a non-palliative lymphoedema service under an AQP contract as an extension to the existing experienced hospice lymphoedema service.

Approach used

- Hospice managers attended AQP stakeholder meeting.
- Submission of tender documentation.
- Acceptance of contract.
- Redesign of current service to accommodate new contract for wider geographical area.
- Recruitment, training of additional staff.
- Set up of data collection to meet requirements of contract.
- Setting up good working relationships with the other 3 commissioned AQP providers.

**Outcomes**

- Patients who are classed as non-palliative have the benefit of an excellent well established palliative lymphoedema service.

Application to hospice practice.

- The hospice now receives full funding for non-palliative patients.
- The hospice lymphoedema team are able to access additional training and gain knowledge of different conditions, this ultimately extends the range of skills and experience that they have to hand to support palliative patients.
- Non-palliative patients more prepared to accept hospice care should they have further disease recurrence or their condition deteriorates.
- Opportunity for hospice managers to gain experience in AQP commissioning process.

#### 018 ONE STEP BEYOND: WORKING IN PARTNERSHIP WITH CCGS TO EXTEND ACCESS TO BEREAVEMENT SERVICES

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**Aims** The service aims to - Provide access to bereavement support for all bereaved people irrespective of age, culture disability and gender - Assess bereavement need and signpost people pre and post bereavement to bereavement services within their locality - Extend access to advice 24/7 supported by the development of a bespoke bereavement website [www.bereavementsupportworcestershire.org.uk](http://www.bereavementsupportworcestershire.org.uk) telephone help-line service, Counselling and Social Work support - Raise professional awareness about grief by providing bespoke education and training - Raise awareness of the bereavement process and coping strategies of bereaved individuals and families by education and group support.

Approach A formal tendering process resulted in securing a three year NHS contract. A multi-agency project group was formed, including a service user, to develop the operational service model in accordance with the NHS service specification. Outcomes - Widening access of bereavement support to adults and children experiencing sudden death from suicide, RTAs' and unexpected deaths - Multi-agency engagement in shaping operational model - Rapid access to social work and counselling social for the bereaved following self-referral and referrals from Primary Care - Positive evaluations from services users and GPs' - Service user involvement in the formal media launch with South Worcestershire CCG - 193 professionals have attended education programme and positively evaluated - 7401 hits to access information on bereavement website.

## Conference Papers 5

#### 019 RECOGNISING DYSPHAGIA RISK AND COMPROMISED NUTRITION IN PATIENTS WITH ADVANCED CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD): EXPLORING THE ROLE OF SPEECH AND LANGUAGE THERAPY AND DIETETICS

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**Background** Patients with advanced COPD have an increased risk of dysphagia<sub>1</sub> and malnutrition<sub>2</sub>. These symptoms are frequently inter-related and can have a detrimental impact on patients' nutritional wellbeing, frequency of exacerbations and quality of life. Speech and Language Therapists (SLT) and Dietitians possess expertise in the diagnosis and management of dysphagia and malnutrition however their role supporting palliative patients with advanced COPD is not well established.

**Aim** To explore the role of SLT and Dietitian in the screening, diagnosis and management of dysphagia and malnutrition in patients with advanced COPD.

To raise awareness of swallowing and nutrition difficulties in advanced COPD amongst patients, carers and palliative care professionals.

**Approach Used** All hospice patients with a diagnosis of advanced COPD were screened for dysphagia and malnutrition by the SLT and Dietitian over a one month period. Anecdotal qualitative information was gathered on the impact of COPD on aspects of everyday life relating to feeding including shopping, food preparation, fatigue, appetite, ability to eat a meal.

**Outcomes** The majority of hospice patients with advanced COPD presented with a degree of oropharyngeal dysphagia and malnutrition (weight loss and fatigue). Patients were unaware that eating and drinking was affected by COPD, believing that swallowing difficulties and loss of appetite were things they would 'have to put up with'. Patients were unaware that help was available and had no understanding of the role of SLT and Dietitian in supporting their symptom management.

**Application to hospice practice** SLT and Dietitian appear to have important roles in raising awareness and supporting best management of dysphagia and malnutrition in patients with advanced COPD, to optimise their feeding and nutritional wellbeing.

Hospices caring for patients with advanced COPD should proactively screen for dysphagia and malnutrition to ensure these symptoms are recognised and appropriately managed.