

Access to national benchmarked data, which is accessible to the CQC, NICE, NHS Commissioning Board, DoH, Local commissioning groups and local Healthwatch.

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012 IMPROVING THE TRANSITION PROCESS FOR YOUNG PEOPLE WITH LIFE-LIMITING CONDITIONS

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Research Aims To identify the training needs of adult Specialist Palliative Care (SPC) teams to care for young adults and inform the development of an education package for adult SPC teams.

Background The prognosis of life-limiting conditions of childhood has improved with an increase in the number of young people accessing adult SPC services. Adult SPC teams may be inexperienced in caring for the complex needs of these young people.

Methods

- Delphi: An online Delphi process collated expert opinion on format, delivery and content of the educational package in three rounds.
- Focus Groups: Focus groups were held with young people with life-limiting conditions, staff from a local adult hospice and carers. Discussions explored the care and support needs of young people and their families, and the training needs of SPC teams. Data were analysed using thematic analysis.

Results

- Delphi: Consensus was reached on range suggested formats and personnel to deliver the training, and on clinical, psychosocial and practical topics. Training should be delivered as a continuous/rolling programme and not as 'a one-off'.
- Focus Groups: Discussions centred on: challenges of caring for young people; barriers to transition; staff education and training; facilitating transition.

Conclusions The knowledge required by adult SPC teams to meet the complex needs of young people and their families is diverse and extensive. To optimise learning, training should be delivered as a continuous/rolling programme, tailored for content and mode of delivery. A template to guide handover and a single point of contact would facilitate the transition process.

Application to Hospice Practice A series of study days has been designed using the information gathered in this research and will commence in June 2013. A template to guide handover is in development with plans to create a single point of contact to co-ordinate the transition process.

013 CO-ORDINATED AND COST-EFFECTIVE HEALTH AND SOCIAL CARE AT THE END OF LIFE - THE RESPONSIBILITY OF HOSPICES

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Any future model of end of life care delivery in the UK needs increased and more effective partnership working between health and social care agencies. The 2008 Department of Health's End of Life Care Strategy recognised that a cultural shift in attitude within the health and social care workforce is required, and an NAO report (2008) suggested a need for greater input from social care to address ongoing challenges. The 2011 publication from the Palliative Care Funding Review and the Report of the Commission on Funding of Care and Support recommends that there should be better integrated health and social care for those facing the end of life, and that this should be free at the point of delivery. This presentation tracks the development of a new Social Care service by a large UK hospice in partnership with a number of key community providers and commissioners. A number of different models of service delivery which have been developed alongside each other are presented, focussing on three areas:

1. developing a referral process and assessment procedures, as well as delivering personal care packages for people in the last year of life on the locality end of life register.
2. developing short term personal care packages enabling people to be rapidly discharged from hospital.
3. developing a hospice-based co-ordination centre where people's health and social care needs are integrated more successfully and cost-effectively.

Outcomes utilising a range of tools and measures will be presented and an argument will be made that hospices not only have a responsibility, but also the relevant expertise and experience to develop, present and market themselves as end of life care co-ordination 'hubs' taking on responsibility for leading on the provision of integrated health and social care to people within the last year of life.

014 CHALLENGING THE PERCEPTION OF DEATH AND DYING THROUGH DOCUMENTARY FILM MAKING IN A HOSPICE

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Background Health promoting palliative care is a relatively new concept in palliative care that aims to increase public awareness and open discussion in relation to death and dying. A year long collaboration between a documentary film artist and patients and staff in a Scottish hospice addressed these aims. They produced 20 short films and a character led documentary feature film showing different strategies that led to increased vitality at the end of life.

Method The film-maker worked with over 40 patients, family members and staff in the hospice to identify and expand on participants' experiences and develop them as narrative for the wider community.

Following the patients' lead, further research into music and performance arts required collaboration with a music director and choreographer in the day-care ward. An extended period of filming and editing followed, where the material was scrutinised and distilled into portraits and songs.

Results The resulting documentary film follows patients in the hospice and in their homes, reflecting their strength and individuality, their hopes and dreams as well as their struggle with disease as they use music and creativity to mirror their personal

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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.

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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